MODEL OF SUPPORT FOR FAMILY CAREGIVERS OF TRAUMATIC BRAIN INJURY PATIENTS FOLLOWING DISCHARGE FROM HOSPITAL REHABILITATION IN THE OR TAMBO DISTRICT MUNICIPALITY OF THE EASTERN CAPE

by

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DECLARATION

I declare that the thesis titled **MODEL OF SUPPORT FOR FAMILY CAREGIVERS OF TRAUMATIC BRAIN INJURY PATIENTS FOLLOWING DISCHARGE FROM HOSPITAL REHABILITATION IN THE OR TAMBO DISTRICT MUNICIPALITY OF THE EASTERN CAPE** 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 dissertation to originality checking software. The result summary is attached.

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

SIGNATURE

4 October 2018

DATE

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ABSTRACT

The purpose of this study was to explore the experiences and challenges of family caregivers of traumatic brain injury patients in the rural communities of the OR Tambo District Municipality of the Eastern Cape, South Africa in order to formulate a model for their support. The qualitative research design was utilized to explore and describe the experiences and challenges of family caregivers. Hospital records were used to get the prospective population. The research population consisted of family caregivers of patients who had survived traumatic brain injury within a period of eighteen months to three years before the study commenced. Data was collected by individual in-depth semi-structured interviews. Data collection was stopped when data saturation was reached after interviewing nine (9) participants. Data analysis was done through the use of Tesch's eight steps of data analysis while Guba' s model was adopted for data verification. This study has highlighted the diverse challenges that the family caregivers of TBI patients encounter in the poorly developed communities. They expressed different challenges they were experiencing like lack of transport for patients, financial constraints, non-existent health services, lack of support groups and information regarding the condition. A model has been developed and guidelines formulated to empower the family caregivers to be able to have control over their situation.

KEYWORDS

Traumatic brain injury; family caregivers; family; rehabilitation; family systems model; OR Tambo District Municipality.

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Dedication

I dedicate this study to my late dear husband MFANELO GOODMAN MJEKULA, my late parents THUBENI and NOBANDLA MNWEBA, my late sister PUMLA MABECE (Spush) and my late nephew SIPHOSETHU MABECE who all decided to pass on whilst I was busy with the study, before they could celebrate this great achievement as a family with me.

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LIST OF ABBREVIATIONS

BIA	Brain Injury Association
CDCP	Centre for Disease Control and Prevention
CIHI	Canadian Institute for Health Information
FMRI	Fractional Magnetic Resonance Imaging
GCS	Glasgow Coma Scale
ICD	International Classification of Diseases
ITF	International Transport Forum
LIC	Low Income Countries
LOC	Level of Consciousness
OFC	Orbitofrontal Cortex
PFC	Prefrontal Cortex
PTA	Post Traumatic Amnesia
RTMC	Road Traffic Management Corporation
SARTR	South African Road Traffic Report
TBI	Traumatic Brain Injury
VFC	Ventromedial Cortex
WHO	World Health Organization

CHAPTER 1

INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 INTRODUCTION

Traumatic brain injury is a worldwide public health problem, its prevalence being estimated at 1-2% of the population, of which mostly are children, adolescents and adults in the United States (U.S.). The surviving patients are said to be most likely to experience and live with lifelong disability caused by traumatic brain injury (TBI) (Corrigan, Selassie & Orman 2010:72; Dijkers, Harrison-Felix, Maritz, Kreutzer & Arango-Lasprilla 2010:81; Langlois et al 2006:375). Faul, Xu, Wald and Coronado (2010:29) mention that in the US approximately 1.7 million Americans sustain TBI annually, resulting from falls (35.2%), unknown/other causes (21%), motor vehicle crashes (17.3%), struck by and/or against an object or person (16.5%), and assault (10%).

South African Road Accident Fund's (RAF) (2010), reports of motor vehicle accidents (MVA) including pedestrian/vehicle injuries are the leading causes of TBI in South Africa; accounting for approximately 50% of unreported TBI as some with mild TBI fail to seek medical intervention.

According to Meel (2006:695), South Africa has an estimate of 89 000 new TBI cases that are reported annually; with gunshots and stab wounds accounting for 20% of head injuries, falls 25%, motor vehicles, bicycles and vehicle pedestrian accidents account for 50%. Mokhosi and Grieve (2006:302), also established that TBI incidence in South Africa is higher than the worldwide average, with many families being adversely affected, socially, emotionally and economically.

The Road Accident Fund's (2010) annual report shows that over a period of twelve years from1993 to 2004 in the Mthatha area only, there were 2 736 deaths from road traffic accidents. Figures the Road Traffic Management Corporation (RTMC) (2010) released in South Africa, show that the number of accidents with fatalities increased by 0.5% to 10 857 in the 2010 calendar year from 10 805 in 2009.

1.2 BACKGROUND OF THE RESEARCH PROBLEM

Applying the global standard of an average of 20 injuries for each fatality, the expected number of persons injured on South African roads is approximately 275 360 per year. According to Donaldson, Brooke and Faux (2009:72), there is a strong evidence that the recovery of road crash victims in South Africa is poor and as such the road traffic related injuries result in disability.

Registers in the Nelson Mandela Academic Hospital, which is one of the referral hospitals for the eastern part of the Eastern Cape showed that the statistics for traumatic brain injuries for a period of three years only (2011 December to April 2015), has increased dramatically. Motor Vehicle Accidents (MVA) including pedestrian vehicle accidents (PVA) were 222, falls - 33, gunshots - 20, assault as well as poly-trauma - 662. According to these statistics, the numbers increased with the seasons, for instance during the seasons for initiations of boys, incidents of assaults increased because during those times there are episodes of stick fighting and during the festive seasons road accidents increased because of drunken driving and exhaustion.

Providing informal, non-paid care and personal assistance to adults in the family who are physically or cognitively disabled has historically been the primary responsibility of family members in many cultures (National Family Caregiver's Association 2009). Mutual care within families is an accepted orientation and activity but when someone becomes dependent due to chronicity of the disease or old age the care being provided becomes 'caregiving' and is rendered distinct from typical care to concerned families.

Caregiving takes place at home or in the community, by friends and family members and without any financial reimbursement. Family caregivers have a large role to play in the lives of dependent people such as those suffering from traumatic brain injury (TBI). The definitions of what caregiving encompasses are as varied as people who need and provide care.

As a result of the caregiving role, the family caregivers face many challenges related to caring for an adult that used to be independent, which could have an impact on their physical, psychological and social well-being (Marsh, Kersel, Havill & Sleigh 2004:434). With the increase of people suffering from chronic illnesses like HIV/AIDS, complications of diabetes, hypertension and TBI, who need long-term care at home, one can assume that most people will be affected by caregiving at one point or another. According to Langlois, Rutland-Brown and Wald (2006:376), TBI can result in long-term or life-long physical, cognitive, behavioural and emotional consequences as even the mild TBI can cause long-term cognitive problems that can affect a person's ability to perform daily activities.

The abovementioned consequences of warrant acknowledgement of the fact that caregiving situations are diverse and there is a lot that needs to be discovered. There is a need, therefore, for the creation of supportive environments that allow caregiving to continue across illness, age and gender spectrum, fostering positivity and reducing its negative aspects.

Understanding of the caregiving experience shapes the purpose of this research study as it is critical to providing effective support to caregivers who generally have tremendous care responsibilities. Like other chronic conditions, persons suffering from traumatic brain injury get to have caregivers. Depending on the severity of the injury, TBI survivors may require long-term rehabilitation and caregiving (Ketzeback 2012:28) which in many cases become the responsibility of the family members of the TBI survivors (Jumisko, Lexell & Söderberg 2007:356).

Caring for a family member who sustained a TBI involves many challenging experiences (Arango-Lasprilla, Quijano, Aponte, Cuervo, Nicholls, Rogers & Kreutzer 2010:1017; Gan, Gargaro, Brandys, Gerber & Boschen 2010; Jumisko et al 2007:353) and can be difficult to adapt to as they suffer from different complications of the injury which may include that the caregiver provides assistance as low as basic needs like feeding and bathing.

Limited research to-date suggest that the 'invisible disability' that persons with cognitive but not physical problems experience poses unique problems for persons with TBI in accessing health services and maintaining a healthy lifestyle (Nosek, Hughes, Robinson-Wheelen, Taylor & Howland 2006:283).

Patterson and Staton (2009:149) in their research study in USA added that more than 5.3 million require long-term support like holistic counselling techniques after results of TBI mentioned. In recent years the use of explosive devices in armed conflicts has added a new mechanism of injuries which are blast injuries (Norman, Matzopoulos, Groenewald & Bradshaw 2007:695). Previous research indicate that males have higher rates of TBI, often during years when they are most productive in society and in many cases where they are contributing the most to the family income (Faul et al 2010:30).

Lim and Zembrack (2005:34) indicate that the challenges that come with caring for a TBI person can result in a caregiver experiencing overwhelming mental exhaustion and isolation especially when they do not get assistance that they themselves need such as support and education on caring for such a person. In addition, the unpredictability of TBI can mean that even though the patient has survived the trauma one cannot be sure of the extent of patient's recovery so the caregiver may not know how long she/he will carry on providing care and to what extent.

O'Callaghan, McAllister and Wilson (2011:218) assert that those who survive a traumatic brain injury are often left with a combination of impairments that impact upon their ability to function productively in their everyday lives. Adapting to the changes following TBI can be extremely difficult, not only for TBI survivors but also for their families. In the initial stages of TBI the focus is on the survival and physical stabilization of the injured person.

When the patient has survived the family may expect that on recovery he/she may be able to heal fully and lead a normal life as one would after any physical injury. However, this is often not the case with TBI sufferers. Unlike an injury in other parts of the body like a fracture in a limb, the brain cells do not regenerate so the sufferers display physical, cognitive, behavioural and personality consequences and may never return to their pre injury health status (Verhaeghe, Defloor & Grypdonck 2005:1005).

Hyder, Wunderlich, Puvanachandra, Gururaj and Kobusingye (2007:341) state that the problem of TBI is filled with difficulties because of its intrinsically heterogeneous population due to age, injury severity, type and functional outcome. With an estimated 10 million people affected annually by TBI, the burden of mortality and morbidity that this condition imposes on society, makes TBI a pressing public health and medical problem. TBI is often referred to as the silent epidemic due to its associated problems such as those of thinking and memory; which are not often visible; and also because awareness about it among the general public is limited.

The burden of TBI is manifest throughout the world, and is especially prominent in Low and Middle Income Countries which face a higher preponderance of risk factors for causes of TBI and have inadequately prepared health systems to address the associated health outcomes (WHO 2007:341). Chua, Ngui, Yap and Bok (2007:31) indicated TBI to be the 21st century epidemic similar to malaria and HIV/AIDS not restricted to developed countries but to the developing countries as well.

The epidemiological and demographic change in South Africa has also caused the health scenario to change in a very significant manner such that there has been a shift in health priorities. Brain trauma has been regarded as one of the most important health problems in South Africa and results in social, cultural and spiritual crises that lead to problems in families and in communities (Parry 2008:25). Studies done in South Africa on caring for chronic conditions, including TBI survivors and those living with HIV, reveal that sufferers are cared for by their parents, grandparents and family members, or live alone (South African National AIDS Council 2007:34).

Literature indicates that the family caregivers are often elderly women who take care of the children after the death of their parents (Wacharasin & Homchampa 2008:385). Riley (2007:83) identified that the family caregivers face many hardships including social isolation, depression, anxiety, anger, blame, lack of knowledge about brain injury and guilt feelings but stated lack of financial support as the most essential factor that increases stress and decreases the ability to cope in caregivers.

According to Cavallo and Kay (2011:484), the family usually manages the physical problems successfully in the long run, whereas they have more difficulty dealing with cognitive and behavioural problems because they are less predictable and can occur outside of the survivor's awareness. Marsh et al (2005:434) in their study on caregiver burden during the year following brain injury, stated that the impact of physical impairment on caregivers is comparatively short-lived, and caregivers generally learn some practical ways to manage the behavioural problems of the TBI survivor.

1.2.1 Management of TBI

The advent of health information technology and health protocols has assisted healthcare professionals to be able to manage brain injuries efficiently thus preventing the prevalence of deaths from trauma. This success has ironically brought about the challenge of multi-morbidity; whereby multiple chronic illnesses result in disability; increasing caregiving needs (Brennan-Ing & Karpiak 2011:3).

The declining death rate of those who sustain TBI, due to efficiency of emergency services and treatment modalities, has led to a growth in the number of survivors in the communities. They ultimately need to be cared for by their relatives who most of the times are the parents, spouses and siblings.

The current practice in the public and private hospitals is that patients sustaining TBI are treated and discharged after few days, depending on one's condition, to continue recuperation at home. This means that families are suddenly given a responsibility of caring for such survivors on their own. Family systems rapidly shift in the aftermath of injury as they become involved in or are relied upon because they play an essential role in the rehabilitation process of chronic conditions.

The researcher has observed that TBI survivors live with their families following discharge from hospital. The families provide their total care which includes hospital visits, personal hygiene and other basic needs. This may be a challenge to members of the family, who, because of increased urbanization and migration, find themselves having to deal with such a problem as a nuclear family with no strong support systems because extended families are no longer existent.

The compounding influence of role changes and increasing burdens with developing familial needs calls for relevant treatment options for families after brain injury (Thomas & Greenop 2008:29; Oddy, Kreutzer, Stejskal, Godwin, Powell & Arango-Lasprilla 2010:19). However, there are very few studies that have investigated the needs and experiences of family caregivers over time.

The family as an integrated system is perceived by its members as an institution from which all its members can draw strength and support whenever they meet with challenges from their social environment and from outside home (Herbert & Haper- Dorton 2005:18). This perception causes the members of the family to experience frustration and difficulty when they are unable to meet the basic needs of their next of kin. As family members become caregivers they often experience frustration due to decreased personal time, management of behavioural changes, physical disabilities, cognitive deficits and declining ability to carry out daily functions on the part of the patient (Fleminger & Ponsford 2005:1419).

1.2.2 Care of TBI survivors

Because the pandemic of TBI is affecting mainly young adults, caregiving engenders role reversal, which represents a major upheaval for family members who are increasingly taking on the greater part of the caregiving responsibility. This is evident especially parents who had hoped that their children would be the ones to care for them when they are old.

According to Rotondi, Sinkule, Balzer, Harris and Moldovan (2007:14), family caregivers have a responsibility for supporting a person with TBI during the years that follow their injury in spite of the challenges. Families are propelled into the world of hospitals, rehabilitation centres and other acute care settings and longer terms. They often find themselves presented with a bulk of caregiving responsibilities resulting in frequently elevated levels of burden, stress and depression due to the extensive and chronic nature of TBI (Chronister & Chan 2006:191; Chronister, Chan, Sasson-Gelman & Chiu 2010:49).

Rowlands (2011:276) suggest that there needs to be a shift away from considering only a person with injury as the individual who needs health professionals' intervention. The researcher argue that intervention has to be extended to the injured person's resources, network and community. This then means that there is a necessity to understand their needs, strains and coping skills. Despite their important role in caregiving, there has been little research conducted in order to better understand their unique caregiving challenges and coping strategies.

Meeting the needs of caregivers throughout their healthcare journey, from the point of injury and subsequent rehabilitation is essential given the fact that the successful social integration of individuals with TBI is dependent on the conditions they experience after they return to the community. Tara, Arango-Laspirilla, De los Reyes and Quijano (2012:87) stated that TBI has a significant impact on survivors as well as their loved ones, but there has been limited work done towards the development of treatment protocols that simultaneously address the needs of the patient and those of the caregivers.

Family caregivers in developing nations where the burden of TBI is great, have unique barriers like the lack of TBI rehabilitation and community resources and assets, for example, strong social support network that are likely to influence their needs (Arango-Lasprilla et al 2010:1018).

Even though appropriate rehabilitation services may exist in urban areas in South Africa, these are very often not accessible to South Africans living in rural areas (Bryer 2009:205). Though most of the South African population are currently residing in the rural areas (Department of Environmental Affairs and Tourism 2003) there are some health services that are not available to the rural population because of the inaccessibility of healthcare centres to their communities.

The unavailability of appropriate healthcare services to all South Africans is a phenomenon that is prevalent in many developing countries because patients meet with challenges like bad roads and lack of transport before one is taken to a health centre. This results in many patients being unable to receive appropriate rehabilitation intervention in good time.

1.3 STATEMENT OF THE RESEARCH PROBLEM

According to Oddy and Herbert (2003:259), caring for a family member who is suffering from TBI is very challenging considering that TBI survivors may have to confront their disabilities for decades or for their lifetime depending on the severity of the injury. Akintola (2006:23) indicates that caring for such a person is a distressing and stressful activity.

The increased distress can result in caregiver breakdown which can have an effect on the care and rehabilitation or adjustment of a family member with TBI. This may create additional costs as the caregiver will be seeking healthcare and there shall be a need for alternative caregiver for the sick

Primary Health Care and rehabilitation services in South Africa, a country suffering one of the world's largest TBI epidemics, are sparse putting the burden of caring for TBI patients on the family who takes over after the discharge of the patient. The infancy stage in which the Primary Health Care (PHC) services find themselves increases the strain on hospital services mainly due to geographic inaccessibility, unavailability, irregular supply, and sometimes the lack of essential drugs, equipment and as well as lack of appropriately skilled personnel at PHC clinics.

Rehabilitation services are still concentrated at tertiary institutions and private service providers. Based on these Tara et al (2012:88) suggest that healthcare professionals should promote family involvement whilst the patient is still in hospital, to increase the likelihood of a successful recovery for individuals with TBI even when they are home. They are also of the opinion that family caregivers require on-going support in managing caregiving demands to improve health not only that of an individual with TBI but also of their own and their functioning. Wallace (2007:432) posits that family members are able to provide valuable input into the daily experience of the TBI survivors.

The observation by the researcher was that relatives of TBI sufferers in ICU were being overwhelmed by the conditions they found their next of kin in whilst still admitted in hospital. Of note was an increase in the number of the population of adult patients with TBI caused by trauma (stick fights), falls and motor vehicle accidents.

Whereas many studies have examined the long-term toll of coping with family members who have chronic neurological illnesses like stroke and dementia, studies have not specifically examined the subjective burden and practical difficulties of providing care to a family member suffering from TBI caused by accidents and falls. According to the literature review of other countries, caregivers could experience different types of problems while providing care for people living with TBI (Boon, Ruiter, James, Van Den Borne, Williams & Reddy 2009:374).

The perceived lack of knowledge by the healthcare professionals regarding caregiving challenges of TBI patients makes it difficult for the development of appropriate care standards to support family caregivers. It is in this context that the researcher presumes that this study will close the knowledge gap as it will be done in the African soil. This is supported by the study of Parry (2008:35) and Thomas, Nyamathi and Swamithan (2009:994) who have established that there is a need for caregiver-focused research that explores their experiences, challenges, mental wellbeing, family support, social networking and coping mechanisms in their daily living contexts as this will in turn lead to effective and efficient care of patients living with TBI, without compromising the physical and mental health of the family caregivers themselves (Hejoaka 2009:874; Mendez- Luck, Kennedy & Wallace 2009:233).

The current practice in public and private hospitals is that, patients sustaining TBI are treated and discharged to continue recuperation at home, meaning that families are given a responsibility of caring for such patients. According to Oddy and Herbert (2003:259), caring for a family member who is suffering from TBI is very challenging considering that TBI survivors may have to confront their disabilities for decades or for their lifetime depending on the severity of the injury.

O'Callaghan et al (2011:218) state that 80% of people suffering from TBI return to their families following hospitalization and require help from those families. They further mention that the length and degree of recovery of TBI sufferer is closely associated with the health, stress levels and psychological burden of primary caregiver.

The increased distress can result in caregiver breakdown which can have an effect on the care and rehabilitation or adjustment of a family member with TBI. This may create additional costs as the caregiver will be seeking healthcare and there shall be a need for alternative caregiver for the sick. Akintola (2006:23) indicates that caring for such a person is a stressful activity.
The researcher, therefore, wants to answer the following questions:

What information is given to family caregivers regarding TBI on discharge of the patient?

What are the family members' perceptions regarding discharged TBI patients?

What needs and barriers do family caregivers experience when providing care to TBI patients and when communicating with them?

How can the family caregivers be supported while caring for patients suffering from or who survived TBI having been discharged from hospital rehabilitation?

1.4 PURPOSE OF THE STUDY

The purpose of the study is worded in a declarative form stating the general direction of the enquiry (Polit & Beck 2012:88). According to Terre Blanche, Durrheim and Painter (2006:33), the purpose of a study is normally explained in three stages as a general statement of what the research aims to discover, an account of where these aims come from and a rationale for the research.

The purpose of this study was to develop a model of support for family caregivers caring for an adult family member with TBI after discharge from hospital rehabilitation.

1.4.1 Research objectives

The objectives of the study were to:

- Explore and describe the unique experiences of family caregivers of individuals suffering from TBI following discharge from hospital.
- Identify and describe challenges experienced by family caregivers who care for TBI patients following discharge from hospital rehabilitation.

1.5 SIGNIFICANCE OF THE RESEARCH STUDY

The ability to provide care effectively to TBI patients is the fundamental need for family caregivers and is central to the provision of good quality care at home. Equipping family caregivers on how to manage the challenges and experiences of care will empower them on overcoming their plight, improve their safety and reduce complaints of stress and frustration in their provision of care. The significance of this study will highlight the challenges and needs of family caregivers of TBI patients based on their experiences of caring for chronically ill patients in a rural setting.

The major focus of this study is also aimed at providing the health professionals with an understanding of what the family endures when the member of the family has survived traumatic brain injury and is discharged home. The results of this study may contribute significantly to the current research knowledge base of traumatic brain injuries in South Africa and bring insight to the healthcare professionals on the huge task that the families are having.

Finally, it is envisaged that the results of the study shall contribute towards improvement of the quality of care of brain injured patients and support of family members whilst the patient is still admitted in hospital in order to prepare them for what to expect post discharge. When the study is finalized, the developed model shall be presented and applied in order to sensitize the community stakeholders at local, district and provincial levels on the needs of family caregivers. The study will also highlight the need for availability of multi-disciplinary rehabilitative services in the Eastern Cape Province especially the regions which were previously disadvantaged.

1.6 DEFINITIONS OF KEY CONCEPTS

A concept is defined by Polit and Beck (2012:749) as an abstraction based on observations of behavior or characteristics. The concepts have been defined to unpack the theoretical meaning of the concept that is being studied. Conceptual definitions used in this study are as follows:

- **Caregiving:**

This term refers to the provision of unpaid assistance for the physical and emotional needs of another person, ranging from partial assistance to 24-hour care, depending on the care recipient's condition (Goodhead & MacDonald 2007:13). There are often no formal agreements or services specifications in such caregiving, which is often characterized by relationships and social expectations. In this study caregiving is the informal assistance given by family members to a family member following.

- **Experiences of caring**

Concise Oxford Dictionary (2011:406) defines an experience as an event or occurrence which leaves an impression on an individual; to undergo an occurrence or event leading to a feeling or an emotion. For this study, experience of caring for TBI patient is the life-world as lived, felt undergone, made sense of and accomplished by people caring for TBI sufferers after discharge from hospital.

- **Family caregiver**

Is any person who has a relation to a person by blood, marriage, adoption or anyone who is emotionally attached to that person who has an obligation of support giving to his kin (Boyd & White 2009:173). According to Khan, Baguley and Cameron (2003:290), caregivers are people who provide informal care to others in need of assistance or support without being hired for the service. For the study family caregivers are is any adult member of the family actively involved in caring for a family member with traumatic brain injury.

- **Family**

Any group of people related biologically, emotionally, or legally. That is, the group of people that the patient defines as significant for his or her well-being (McDaniel, Campbell, Hepworth & Lorenz 2005:2; Kaplow & Hardin 2007:16). The family of the patients is not necessarily biologically or legally related. For this study, the family is anybody who regards himself/herself as a significant member of the family.

- **Rehabilitation**

Sigurgeirdottis and Halldorsdottir (2007:385) define rehabilitation as a process of restoring a person's ability to live and work as normally as possible after a disabling injury or illness. For the purpose of this study, rehabilitation is the process of retraining people with disabilities following TBI, such as physical, cognitive or otherwise, to return to previous functioning or if this is not achievable; to the most ability that one can achieve in order to be as functionally independent as possible.

- **Traumatic brain injury**

A TBI is a blow or jolt to the head or a penetrating head injury disrupting brain functioning and impacting activities of daily life, most often creating unexpected dependence on others (Brain Injury Association 2009). For the purpose of this study TBI is any injury to the brain that occurred through trauma and has led one to have a disability, permanent or temporal, whether cognitive, physical, psychosocial or otherwise.

- **Traumatic brain injury survivor**

Is a person who has recovered from a traumatically induced structural injury and/or physiological disruption of the brain function as a result of an external force. For this study is the person who survived brain trauma whether mild moderate or severe and has been discharged from hospital.

1.6 THEORETICAL FRAMEWORK

A theoretical framework provides a particular perspective or lens through which to examine a topic, disclosing the methods, theoretical perspective and epistemology underpinning the research. This research study used the family systems as a theoretical framework (Rolland 1999:242; Prest & Protinsky 1993:353). This theory is relevant for traumatic brain injury which has long-term consequences on both patients and family.

The implications of the family systems theory to this study is to focus not only on the individuals that compose caregivers but also the patterns and interactions of family members in their contexts as people because the family systems framework is the premise for all family therapy interventions (Gurman & Kniskern 2014:3). This is because a holistic view of the family system avoids singling out one family member; the individual does not live in a vacuum, as a social being he is always in interaction with other social beings within the environment.

Moreover, researchers have consistently demonstrated that the most effective family intervention approaches are those that conceptualize the family as a functional unit and treat the family as a whole (Gan, Campbell, Gemeinhardt & McFadden 2006:588).

According to family system's theory (FST), the researcher requires more than gathering perceptions from or about a single person but characteristics and qualities that are a product of the interrelatedness of people (Friedman, Bowden & Jones 2003:211; Becvar & Becvar 2009:10). Family system's perspective views families as interacting as a system, adjust to change in their environment and define their boundaries.

In addition, Family Systems Theory embraces concepts from the social constructionist school of thought in order to describe the way in which all rules and boundaries allow the system to be clearly defined and to function effectively (Becvar & Becvar 2009:12). Within this framework, all roles and experiences within the family are not only connected, but work in a manner in which all rules and boundaries are co-constructed by the members of the family system. Effects within the family system and larger systems to which it is related are therefore far-reaching.

The family systems theory is based on concepts that are its building blocks. Bowen (1978:75) realized that in order to be able to make a good diagnosis to a patient the health practitioner has to take into consideration the family first because he discovered the significance of the family on a person's emotional development. He not only views the family as an organic unit but also recognizes universal patterns that govern a family's management of anxiety. In a systems theory an emotionally disturbed individual is not only the product of the family's dynamic constitution but also a predictable component of the family's operating system which has been in operation for a long period of time maintaining the family survival.

While a mature and psychologically healthy individual develops a differentiation of self, most family members instead formulate identity through their family's emotional characteristics. Consequences of this sacrifice of self can range from experiencing minimal levels of anxiety to severe emotional and/or physical illness. Therefore, the family therapy's primary goal is to help the involved family members to differentiate clearly defined 'selfs' from undifferentiated ego mass. When one talks of differentiation of self from the family system it means that one is recognized as a unique being with a unique position in relation to other members in the family structure.

In order to understand the family systems theory, the researcher discussed the concepts that make up the theory. These concepts are the products of the universal emotional system that guides all our maturation within the family unit. By realizing how we all are determined by these concepts in our relationships with others, it is purported that we can recognize our patterns and thereby function as healthier beings. The family system is more about human beings integrating and interacting within a relationship.

Triangles

The concept of angles explains the tendency of individuals relating to each other in systems of three. Triangles occur because dyads or two person relationships are unable to contain or absorb stress and anxiety. This concept is aimed in showing that emotional stresses are better attended to by more people than two and to determine the emotional processes involved in triggering symptoms.

Differentiation of self

This is defined as the degree to which one self-fuses or merges into another self in close relationships, self in this context meaning the ability of one adhering to one’s own principles and goal directedness no matter the amount of pressure or anxiety one is experiencing.

A person with a well differentiated self recognizes his realistic dependence on others, but he can stay calm and clear headed in the face of conflict, criticism and rejection to distinguish thinking rooted in a careful assessment of the facts from thinking clouded by emotions, but if one does not have enough self to accomplish his goals one manipulates his way by mechanisms like bullying and guilt.

The challenge of becoming a functional individual is to develop a self that is able to hold one’s goals, beliefs and values while respecting those of others and without being emotionally determined by the pressures of the family system (Bowen 1978:117).

The nuclear family emotional system

Nuclear family emotional system is comprised of four basic relationship patterns by which all families, to some degree function. Some families only operate according to one model while others exhibit characteristics of them all. The degree to which these families adhere to these patterns in order to assuage anxiety determines their ability to function.

Family projection process

Family projection process is a process to which an individual uses to transmit fears and anxieties to willing others. This makes it possible for the family to identify change in one's behaviour who wants support.

Multigenerational transmission process

This concept allows for a systematic reading that extends beyond the nuclear family and into extended family. Small differences in the levels of differentiation between parents and their offspring and between members of a sibling group lead over many generations to marked differences in differentiation among the members of a multigenerational family.

Emotional cut off

Emotional cut off is the sixth concept being the driving force of nuclear family emotional pattern, emotional distance means the ability of an individual to manage unresolved emotional issues with siblings, parents and other members of the family by reducing or cutting off emotional contact with them. Research has shown that people who tend to cut off relationships and distanced themselves from significant relationships tend to suffer from depression or other serious mental illnesses.

Sibling position

Siblings influence the behaviour and characteristics of the person. An individual's sibling position within his or her family and the mix of genders in that configuration predictably imparts identifying characteristics onto his or her emotional and mental development.

The caregivers are viewed as whole persons with body, mind and spirit in interaction with their external and internal environment which comprise their physical, social and spiritual dimensions. They do not undergo this process in isolation as the process affects their subsystems. To them reality is understood by breaking experiences up into small parts and if these small parts are understood then the reality of experiences can be understood (Gan et al 2006:588). This will form a foundational approach towards answering the research question so as to make sense of the experiences of family caregivers of TBI survivors and in formulating a model of support in caring for TBI patients.

1.7 PARADIGMATIC PERSPECTIVE

According to Polit and Beck (2012:13), a paradigm is a worldview and a general perspective on the complexities of the real world. Any process of formal inquiry is guided by a set of basic beliefs and or philosophical inquiry.

In approaching this study, the researcher acknowledges the complexity of research phenomenon and believes that a holistic approach is especially suitable for studying a phenomenon such as experiences of family members caring for their TBI survivors post discharge from hospital.

The ideas that form the foundation of a research paradigm are formed to answer three questions concerning the nature of the reality which is (ontological perspective of the study) how we get to know the world, the relationship between the researcher and knowledge (data collection and analysis) - epistemology- and how the inquirer should go about finding the knowledge (methodology) which is the practical means of how to know the actions of research (Polit & Beck 2012:13).

The researcher used the naturalistic paradigm. Naturalistic method of inquiry attempts to deal with the issue of human complexity by exploring it directly. Researchers in naturalistic traditions emphasize the complexity of humans, their ability to shape and create their own experiences, and the idea that truth is a composite of realities. Consequently, constructivist investigations place a heavy emphasis on understanding the human experience as it is lived, usually through the careful collection and analysis of qualitative materials that are narrative and subjective (Polit & Beck 2012:17).

In this paradigm the search for meaning involves the analysis of descriptions or discourse that people continually construct, develop and change. Their interpretations of their worlds should be taken into account in any social science research (Babbie & Mouton 2009:28). For this study the researcher will seek to explore the experiences of caregivers of TBI survivors after discharge and to formulate a model for caring. Experience is people's perceptions of their presence in the world. Perceptions present people with evidence of the world - not as it is thought but as it is lived. This puts the study in an interpretive framework. The analysis of particular existential facts proceeds from an interpretation of the relevance it has to existence.

A generic qualitative research approach was used. Qualitative research follows an inductive, subjective approach and the focus is on how people make sense of their world. The reason for using this approach is because it allowed knowledge to be generated about family caregiving of TBI survivors. The insistence on an interpretive understanding of the meanings and self- descriptions of the individual requires a methodology which emphasizes unstructured observation, open interviewing and qualitative data analysis (Babbie & Mouton 2009:33).
Henning, Van Rensburg and Smit (2004:3) define qualitative research as a quest for understanding a process and as methodological study of a chosen problem. A qualitative approach was selected because rich descriptive data are desired to document experiences and realities of caring for TBI survivors.

Qualitative research is grounded in the assumption that features of the social environment are constructed as interpretations by individuals and that these interpretations tend to be transitory and situational. Thus within the qualitative paradigm the entity to be studied was the life world of the family caregivers as it was experienced individually. The life world under investigation was the phenomenon of caring for traumatic brain injured patients at home post discharge from hospital rehabilitation and the challenges these caregivers encounter.

1.7.1 Assumptions underlying the study

Assumptions are basic principles that are accepted as being true based on logic or reason without proof or verification (Polit & Beck 2012:14). Assumptions indicate the scholars' insight into their research, their ability to reconcile ontology, epistemology and methodology (Brink, Van der Walt & Van Rensburg 2006:3). Assumptions in this study were as follows:

1.7.1.1 Metatheoretical assumptions

The metatheoretical assumptions for this study were derived from the interpretive perspective with a qualitative approach. For this study the researcher sought to understand the caregivers' interpretations of reality which is caring for TBI patients post discharge from hospital.

1.7.2.2 Ontological Assumptions

Reality is not a fixed entity but is rather a construction of the individuals participating in the research. According to constructionists, reality is multiple and subjective, mentally constructed by individuals within a context which is having possibility of being reconstructed as there are always multiple interpretations of reality that exists in people's minds. The researcher interacted with those being researched. The researcher endeavoured to minimize the distance between self and the participants as this paradigm assumes that knowledge is maximized when there is less distance between them.

For this study the assumptions regarding the experiences of family caregivers were that:

- If the family is perceived as a system and the assets that it can bring to the process of intervention are identified, all involved can benefit in the long run, including health practitioners, the patients and their families.
- Family members participating in the study are truly representing the family unit's caregivers and that enough members of multi-caregiver families participate to provide a valid representation of the TBI victim's family caregiving unit.

1.7.2.3 Methodological assumptions

Methodological assumptions are the views of the researcher about the nature of science and research in a study. These assumptions guide the researcher in the selection of the most appropriate methods to be used in a study. Methodological assumptions focus on analysis of the methods used for gaining the data.

Methodological assumptions for this study were:

- Semi-structured interviews were ideal for interaction with the family caregivers and to obtain narrative information regarding caregiving.
- An interactive process between the researcher and the participant would provide information on which to base an interpretation.
- Provision of support for family caregivers ensure good quality of life for them to cope with their tasks.

1.7.2.4 Theoretical assumptions

The theoretical assumptions of this study were that:

- Family caregivers' experiences and the meanings they assign to those experiences are necessary to generate data that will assist the researcher in the formulation of guidelines of care.
- The discovery of knowledge is understood as the creation of an interaction between the researcher and the researched.
- Interpretations of experiences of family caregivers of TBI patients are important to understanding the life-world of caregivers.

1.8 RESEARCH DESIGN AND METHODOLOGY

A research design is a plan, structure and strategy of investigation, so conceived as to obtain answers to research question/s (Babbie & Mouton 2009:74). The purpose of the research design is to achieve greater control on the variables, thus improving the validity of the study in examination of the research problem (Burns & Grove 2009:292). A qualitative, exploratory, descriptive and contextual research design was utilized in order to gather in depth information from the participants (Creswell 2009:4) on the experiences of family caregivers of TBI survivors post discharge from hospital. More details regarding the research methods and design is presented in Chapter 3.

Ethical considerations were also adhered to in order to ensure the scientific status of the study. These are also discussed fully in Chapter 3

1.9 ORGANISATION OF THE STUDY

The content of thesis is organized into seven interrelated chapters. These chapters are outlined as follows:

Chapter 1	Introduction and background to the study
Chapter 2	Literature review
Chapter 3	Research methodology
Chapter 4	Data analysis, presentation and description of the research findings
Chapter 5	Discussion of findings and supporting literature
Chapter 6	Model for support of family caregivers of patients with traumatic brain injuries
Chapter 7	Conclusion and recommendations

1.10 CONCLUSION

In this chapter the researcher presented the background of the study, problem statement, purpose and objectives of the study, theoretical framework and definition of concepts. In the next chapter literature review is presented.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter discusses the review of literature on traumatic brain injuries globally, nationally and provincially and the theory underpinning the study which is a family systems theory. According to Polit and Beck (2012:213), literature review is an evaluative report of information that is found on literature search that is related to the topic that is being researched, which contains information, ideas, data and evidence written from a particular standpoint to fulfil certain views on the nature of the topic. It explains how the topic is to be investigated and the effective evaluation of these documents in relation to the research being proposed (Hart 2003:13). This review will explore the experiences of family caregivers in relation to what other researchers have observed.

Polit et al (2012:218) suggest that a thorough literature review provides a foundation on which to base new evidence and suggest that conducting an extensive literature review builds the study firmly within a body of published research and integrates the specific problem of study within the existing theory.

The researcher uses revelations from existing findings to progress to new information that will attempt to answer the research question of the study. A good literature review should be able to provide context of the research study, highlight the flaws in the previous research and should help refine or/and change the topic.

The main focus of this literature review is on family caregivers of TBI survivors after discharge from hospital, researching the question of how they experience provision of care to a TBI patient so as to provide new insights into the relationship between the survivor and family caregivers' outcomes that are important for the design of an effective health program to prevent caregiver morbidity and family breakdown. The researcher will also review literature on TBI so as to understand the condition of TBI.

According to the statistics by the Brain Injury Association of America (BIA) and the Centre for Disease Control and Prevention (CDCP), an estimated 5.3 millions of American citizens live with disabilities from traumatic brain injury as about 80 000 to 90 000 of Americans sustain TBI related disabilities which result in long-term residual disability annually. TBI patients after discharge have to go back to their communities and homes where they display the sequelae of their condition. The relatives have to endure all these sequelae in silence. The numbers that the researchers display when talking about TBI, therefore, tell nothing of the pain and suffering the family caregivers undergo as they share in the recovery journey of the patient.

2.2 TBI INCIDENCE IN SOUTH AFRICA

The researcher discovered little literature relating directly to the South African perspective regarding TBI; therefore, the literature reviewed here is drawn from a range of international resources, with the aim of providing a framework applicable to the researcher's study within the South African context. Although there may be observable differences in terms of context, ethnic background and availability of resources between different countries, there are also common basic similarities of TBI experienced globally among families.

Therefore, though a number of the studies that were used in this literature review were based on results from First World countries; they have shown that the effects and impact of TBI on survivors and their families is fairly similar across all cultures (Al-Adawi, Dorvlo, Burke, Huynh, Jacob, Knight, Mrugeshkumar, Shar & Ala'Aldin 2004:435).

It is important to note, however, that although experiences in a country like South Africa may be similar to the experiences of TBI in developed countries, from which literature was searched, the degrees of stress and the amount of needs within these experiences are vast.

The World Health Organization (2006:164) describes neuro-trauma as a critical public health problem that deserves the attention of the world's health community. Estimates of brain and spinal cord injury occurrence indicate that these injuries cause enormous losses to individuals, families, and communities. They result in a large number of deaths and impairments leading to permanent disabilities.

According to Hyder et al (2007:341), in Latin America and sub-Saharan Africa an incidence rate of traumatic brain injuries of between 150 and 170 per 100,000 is due to road traffic accidents compared to a global rate of 106 per 100,000 while the World Health Organization has predicted that road accidents alone, which account for many instances of TBI, will constitute the third largest contributor to the global burden of disease and disability, after heart diseases and depression by 2020 and will be in second place in developing countries.

Incidence rate for TBI in rural South Africa tend to be higher than in the urban settings though there are some inconsistencies regarding the reporting of TBI, with violence and substance abuse being significant contributors to this trend and the tendency of not reporting the incidences. Compared to global trends, the death toll on South African roads is extremely high. Theron (2004:344) further reports that approximately 11 accidents and/or deaths occur per hundred kilometres travelled. South Africa's traffic death rate is eclipsed only by that of Korea, Kenya and Morocco, while it is marginally higher than that of Brazil and Chile.

The Road Traffic Management Corporation (2010) in South Africa reported approximately 40 deaths per day and 15 000 deaths annually. South Africa's road traffic death rate far exceeds the global middle-income country mortality rate of 18.01 per 100 000 (WHO: 2015). In fact, South Africa was recently ranked by the International Transport Forum's (ITF 2012) latest road safety annual report as the worst, out of 36 countries, when it came to the number of road accidents.

Road mortalities per 100 000 inhabitants stood at 27.6 deaths in 2011, a shocking statistic when compared to HICs in North America with 10.4 deaths per 100 000 inhabitants, or Australia with 5.6 per 100 000 inhabitants. The road mortalities for the low income countries (LICs) included in the report also did not exceed South Africa's road death toll, with approximately 12 mortalities per 100 000 inhabitants being reported in both Argentina and Colombia and 23.8 per 100 000 inhabitants in Malaysia (second worst). The report included provisional data that showed that, in South Africa from 1990 until 2011, the number of mortalities increased by 25%.

Nevertheless, although the motorized fleet in the country has doubled in the last 20 years, fatal crashes decreased from 14 000 in 2011 to 12 200 in 2012. Pedestrians are particularly at risk and represented more than 35% of all the reported mortalities in 2012 (NIMSS 2013; Sukhai, Jones & Haynes 2009; ITF 2012). The NIMSS also contains South African pedestrian mortality data that reflects that the 15 to 45 years age group is the highest risk group, followed by the 0 to 14 years age group (Statistics South Africa 2016).

According to Peek-Asa, Zwerlink and Stallones (2004:1689), poverty, family problems and inadequate education are factors that also contribute to the injuries like TBI. This report is an issue of national concern for South Africa, and demands a considerate response. Mokhosi and Grieve (2006:302) concede with this statement and add to the aforementioned factors that sport and falls also contribute. They state that as is the case with the developing countries it is estimated that the incidence of TBI in South Africa is higher than the worldwide average, the population at high risk being males and that these injuries mostly occur during Easters and Christmas times, when it is time for festivities.

In South Africa the ratio of male to female incidence of TBI is estimated to be 5:1 compared to worldwide estimated ratio of 2:1. This is thought to be due to the disproportionate contribution of interpersonal violence among the particularly young Black males, as per the study that was done by Nell in 1999 (Mokhosi & Grieve 2006:302). In a research by Blair (2007:386) it is stated that TBI is predominantly caused by motor vehicle accidents (MVA) and interpersonal violence.

International research has established a relationship between TBI and criminal behaviour in both child and adult populations because adjectives such as impulsive, aggressive, having a lack of empathy and displaying mood swings are often used to describe juvenile delinquent behaviour (Slaughter, Fann & Ehele 2003:731).

In a study on juvenile delinquency it was discovered that the types of injuries that frequently occur to young people can cause damage to the prefrontal cortex which may result in aggressive and psychopathic behaviours that are characteristic of criminal behaviour (Blair 2007:387; Farrer & Hedges 2011:390). This breakdown often leads to psychopathy which is frequently associated with criminal behaviour consequently resulting in life persistent conflict with the law (Blair 2007:388).

Sports and recreation activities are also a major cause of TBI including concussions and are severely underestimated using the existing national data sets. Research study by Schulz, Marshal and Mueller (2004:937) on TBI in sport also suggest that injuries involving loss of consciousness may account for between 8 and 19.22% of sport related TBIs.

There is also a high incidence of pedestrian accidents because the heavy pedestrian load in economically disadvantaged suburbs increases the injury risks for people on foot. As is the case in many developing countries, it is estimated that the incidence of TBI in South

Africa is higher than the worldwide average as a figure of 316 per 100 000 a year for the Johannesburg area has been reported. It is further estimated that of those injured, 10% die and 90% are hospitalized. Of those hospitalized, on average 80% are hospitalized with severe brain injuries, 10% with moderate injuries and 10% with mild injuries (South African Road Traffic Report 2009).

Research has also documented the fact that those who survive a traumatic brain injury are often left with a combination of impairments that impact upon their ability to function productively and independently in their everyday lives and are likely to experience permanent residual impairment as a result of their brain injuries. Adapting to these changes can be extremely difficult, not only for adults with TBI but also for their families (Masket, Chiarelli & Isles 2007:741; Testa, Malec, Moessner & Brown 2006:236).

It is estimated that the authentic statistics on incidence of TBI in South Africa are currently not available because some victims do not seek medical care or report their injuries, but given the nature of inaccessible and expensive healthcare it is likely that a large number of mild TBI cases remain unreported. Routinely reported national data underestimate the true burden of traumatic brain injuries for several reasons which include the fact that they do not include persons treated for TBI in other settings.

In a study by Finkelstein, Corso and Miller (2006:187) on the incidence and economic burden of injuries in the United States, they concluded that additional persons treated in hospital out-patient settings or physicians' offices and those who do not seek medical care after injury are not diagnosed as TBI, hence are not included in the statistics. In spite of failure to report in healthcare facilities TBI patients do ultimately suffer the consequences of TBI and are not budgeted for in the country's health budget. Taking this into consideration a more accurate approximation may be that the numbers estimated are very low because many of these injuries go unrecognized and thus unaccounted for.

Before the advent of health information technology, the problem of traumatic brain injury patients was not so prevalent in the world. According to Stebbins and Leung (1998) as quoted in Degeneffe's (2009:13) study, the number of people surviving TBI has increased significantly in recent years because of faster and more effective emergency care, quicker and safer transportation to specialized treatment facilities, and advances in acute medical management.

These medical services made it possible for rapid diagnosis and sophisticated treatment of patients with neurological injuries. Many who would have died in the past as a result of the severity of their injuries now survive because of the advances in the healthcare technology.

Now the number of people who survive severe traumas and brain injury has increased substantially over the last few decades, however, they often survive with disabilities, leaving the nation's healthcare system with yet another challenge - an entire new patient population in need of long-term treatment and rehabilitation from their injuries.

The population of TBI sufferers is sure to grow to old age by 25% of the total population by year 2030 because of availability of advanced technology. Not only is the acute care in the hospital setting extremely important, but also, traumatic brain injury patients need major care beyond hospitalization. Unfortunately, for many TBI patients, very few programs have been developed to provide medical and societal support after the initial medical crisis. This study has its relevance not only in the additional understanding it can provide of family caregivers experiences but more broadly on contributing to the growing of neurological research in South Africa.

Prevalence of diseases may be universal but the availability and access to healthcare services differ according to countries. Despite the progress made on specific initiatives to deal with the problem of caring for traumatic brain injury survivors, very few countries have developed comprehensive systems that meet the needs of people with traumatic brain injury and of their families. Some have made significant gains in addressing selected aspects of the overall problem, but progress has been sporadic, as it has been dependent on the service delivery philosophy of each country, and on individual strategies for dealing with the problem.

Access to healthcare in South Africa is linked to the economic structure of the country and TBI has to be viewed against the background of access to healthcare services (Reynold, Paniak, Toller-Lobe, Nagy & Schmidt 2003:139).

In South Africa, there are services for the wealthy and those of the poor and the socioeconomic status of the family dictates, to a degree, the kind of access to healthcare the family enjoys. Even if one is able to pay for such services rehabilitation services in our hospitals are not comparable to international standards and practices. Although sizeable public expenditures support the needs of TBI patients, family members do the caring after hospitalization, often without adequate professional support and intervention. After twenty years of democracy, South Africa still has an uneven racial distribution of poverty (Social Development Report 2009). The indigent people of South Africa have access to

free healthcare within a primary healthcare model and a very basic system of state welfare exists but is barely adequate to meet the basic needs of the people.
The government services are not accessible to all those who require financial support for basic living because of the distances that people in the rural areas need to travel to access social welfare structures. According to the Department of Environmental Affairs, 80% of the SA population live in the rural areas where there are little opportunities for employment and if the opportunity is there it is informal employment, so the wages they get do not allow them to pay for private medical care.

The most common solution for rural populations is to allow all those who are still employable, especially males, to leave traditional homes to seek employment in big towns to work in places like mines. They leave their homes with single parents or parentless, sometimes only to return home into the rural areas when they are afflicted by diseases like HIV/AIDS and TBI, to be cared for by their relatives in dire conditions. In spite of this aforementioned plight, little emphasis has been placed on the development of organized services for extended rehabilitation and trauma care in rural settings.

Some facilities have sprung up in urban societies in order to deal with multiple physical, psychological, and social needs of this new patient population, but this is generally a drop in the ocean as the population increases every year and some of the services are inaccessible due to privatization of health services. South African society requires to have increased specialized rehabilitation wings in hospitals, freestanding rehabilitation centres and nursing homes in all the communities regardless of their economic status because the problem of traumatic brain injuries is prevalent in all societies.

2.3 TRAUMATIC BRAIN INJURY VERSUS HEAD INJURY

Confusion exists regarding head injury (HI) and TBI. Head injury is a non-specific and antiquated term which includes clinically evident external injuries to the face, scalp and calvarium such as lacerations, abrasions and contusions whereas TBI is more properly defined as an alteration in brain function manifesting as confusion, altered level of consciousness, seizures, coma and focal sensory or motor neurological deficit resulting from blunt or penetrating force to the head.

According to health informatics, TBI diagnosis is done through the use of International Classification of Diseases (ICD) (1980) coding ICD 9 system using the following rubrics:

- 800.0 - 804.9 Fracture of the skull
- 850 - Concussions
- 851 - Cerebral laceration and contusion
- 852 - Subarachnoid, subdural and extradural after injury
- 853 - Other and unspecified intracranial haemorrhage after injury
- 854 - Intracranial injury of other and unspecified nature

(Burns & Hauser 2003:2-3)

The initial extent of damage, the degree of acute disruption of brain physiology, and, in turn, clinical presentation of TBI varies greatly across individuals, with classification of injury severity an important predictor of both short- and, to a lesser extent, long-term outcome (Corrigan et al 2010; Roebuck-Spencer & Sherer 2008:411).

TBI is distinguished from other forms of brain damage in that an external force acts on the skull causing damage to the brain, the most affected part being the part of the brain that is immediately beneath the point of impact. Stuart and Zafonte (2004:329) argues that the high prevalence of TBI and its potential severity has led brain injury to be regarded as a ‘silent epidemic’ due to the widespread lack of knowledge about it.

According to the Canadian Institute for Health Informatics (CIHI 2006), information pertaining the occurrence of TBI is of importance as it allows for identification of at risk populations and hazardous exposure circumstances and, concurrently, facilitates appropriate planning and monitoring of both prevention and treatment measures. Traumatic brain injury is categorized both by means of injury as well as its severity and can be classified either as open or closed brain injury.

2.3.1 Open traumatic brain injury

The essential feature of open brain injury the skull and the meninges are penetrated by an external object with the subsequent passage into the brain parenchyma. Gunshots wounds are said to be the leading cause of open head injuries (Lezak, Howieson, Loring, Hannay & Fischer 2004:36). In the case of a puncture wound and low velocity projectile primary brain damage may be largely concentrated in the path of the infiltrating object with the tract of destruction related to the diameter of the missiles.

The extent of the injury then depends on the velocity and mass of the object. The increased velocity and mass of the object the higher will be the kinetic energy transferred from the missile to the brain tissue. Intracerebral haemorrhage is an immediate and frequently observed of penetrating head injury and evidence suggest that such haemorrhage may play a significant role in pathogenic cellular cascades.

According to Espositor and Walker (2009:249), subarachnoid haemorrhage occurs in 31 to 78% of penetrating head injuries with its presence shown to correlate significantly with mortality. Clinical reports indicate that limiting intracerebral haemorrhage in patients with penetrating head injury favourably influence the outcome and recovery (Giese, Koops, Lohlman, Westphal & Puschel 2003:268).

2.3.2 Closed traumatic brain injury

The closed head injury is brought about by the mechanism of either static or dynamic loading with the skull remaining unpenetrated. Static loading occurs when forces are applied to the head in a gradual and slow manner. This uncommon mechanism is in operation when the head experiences a slow squeezing effect between opposing forces. Dynamic loading occurs in instances in which the brain is subjected to rapid acceleration/deceleration forces and is the more common mechanical input causing closed head injury as in motor vehicle accidents.
Dynamic loading may be subdivided into two types – impulsive and impact.

- Impulsive dynamic loading takes place when the head is set in motion rapidly or when the moving head is brought to a sudden stop without being struck, resulting in inertial forces that injure the brain.

- Impact loading, the more frequent form of dynamic loading occurs when a blunt object strikes the head or vice versa and typically leads to brain damage secondary to a combination of contact and inertial forces.

The hallmark of a closed brain injury is the violent and unnatural movement of the brain within the skull. It is the movement and 'bouncing around' inside the bony skull that produces the predictable pattern of traumatic brain injury (Morales, Marklund, Lebold, Thompson, Pitkanen & Maxwell 2005:971).

In order to understand the nature of TBI and its subsequent impairments it is important to understand the basic locations and functions of the brain. Hughes (2010:13) states that the brain is the most complex and delicate organ of the body with billions of individual nerve cells clustered together into areas of specializations. The brain is involved in the control of mediation of nearly every aspect of our behaviour, thoughts and emotions ranging from breathing to composing symphonies.

Hemispheres of the brain are two being the left and the right, each specializing in various tasks and functions. The degree to which each side of the brain controls a function is called lateralization.

Speech, verbal reasoning, mathematics, scientific insights and language for most people are highly lateralized being controlled primarily by the left hemisphere; the right side of the brain has to do with the non-verbal aspects of language like humour, visual spatial and rhythmic concepts.

Externally the brain is protected by the cranium and internally covered by three protective types of tissues or meninges called dura, arachnoid and pia maters. The subdural space is situated between the dura and arachnoid and contains a film of water with vulnerable blood vessels that can easily be injured.

When blood accumulates in the subdural space after injury, it has no method of escape and causes subdural haematoma creating pressure on the brain that is concerned with more complex mental activities.

Functional magnetic resonance imaging (MRI) has demonstrated that the prefrontal cortex (PFC) is a common site of neural damage from TBIs. Two areas of PFC are pertinent to the relationships between frontal lobe lesions sustained by TBI and aggressive behaviours: orbitofrontal cortex (OFC) and ventromedial frontal cortex (VFC). Damage to OFC may lead to a lack of inhibition, impulsivity, aggression and a general dysregulation of behaviour.

Damage to the VFC can result in an inability to delay gratification and a lack of cognitive flexibility and abstract reasoning (Fabian 2010:209).

All these processes are linked to the executive functions and the regulation of behaviour. Lesions to these areas may result in dysregulation of behaviour and may lead to reactive aggression.

Reactive aggression is a non - goal orientated violent response to a frustrating situation or a situation that is perceived as threatening (Blair 2010:209). VFC dysfunction is often associated with psychopathic behaviour in adults.

The structures of the VFC may result in a breakdown in care based moral reasoning.

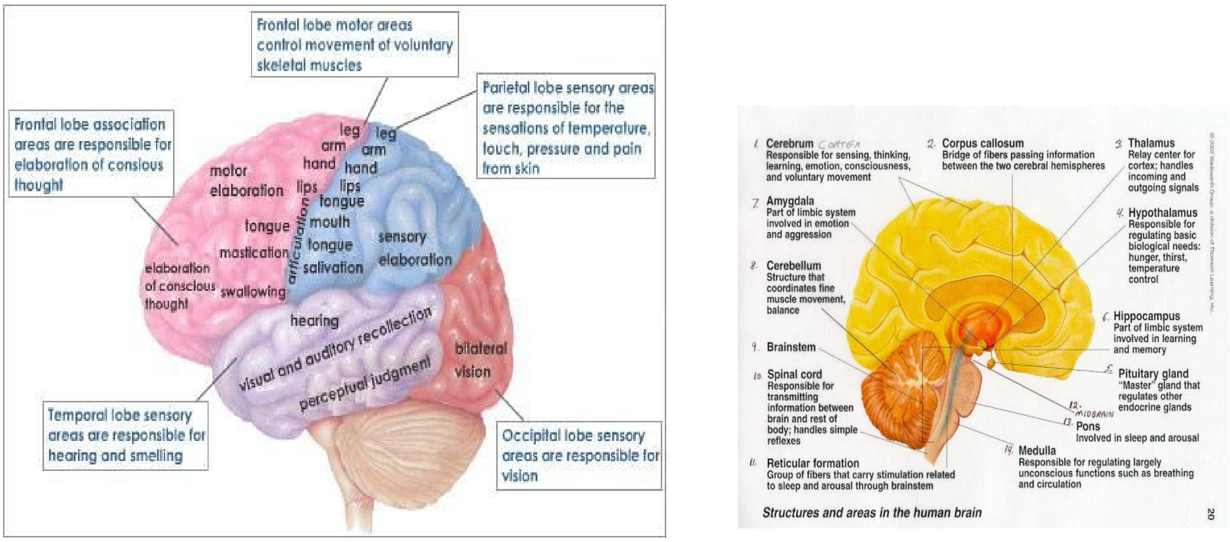

Figure 1.1 Different areas in the brain

(http://www.geneticdisorders.info/article/546521634/brain-structure-and-function/)

2.3.3 Physiology of traumatic brain injury

Traumatic brain injury occurs in two phases: primary and secondary injury. Primary injury occurs upon impact and causes initial tissue damage. Secondary injury refers to those processes that occur after the initial injury.

Secondary injury is caused by either intracranial or extracranial factors and both lead to further brain damage and ischemia (Muller-Esteri 2006:243; Dutton & McCunn 2003:504) state that brain injuries are unlike broken arms because the cells do not regenerate.

According to the Monro Kellie doctrine, the cranial vault is a closed system which holds the brain tissue, cerebral spinal fluid and blood. Increases in volume of any of these substances causes a decrease in the other two until the brain can no longer regulate changes and intracranial hypertension which may lead to herniation of the brain tissue occurs. Alteration in cerebral blood flow is a factor which occurs as a result of changes in the cerebral vasculature and impaired cellular integrity (Bader 2006:246; Barton, Hemphill, Morabito & Manley 2005:2).

Studies have evaluated how changes in cerebral blood flow occur following TBI and they found out that there are three patterns of flow after the initial injury. In the first 24 hours after injury hypo-perfusion occurs due to increases in microcirculation resistance. The next 24 to 96 hours are characterized by hyperaemia, hyper-perfusion and some degree of vasospasm. The final phase occurs between day 5 and 14 which is marked by vasospasm and reduced perfusion.

2.3.4 Severity of traumatic brain injury

The extent of damage, the degree of disruption of physiology and the chemical presentation of TBI varies across all individuals depending on the individual's pre-injury health status. The most commonly used instrument to measure severity of TBI is called a Glasgow Coma Scale (GCS) which is a metric designed to assess the depth of coma in the acute period following injury by determining the individual's responsiveness level in eye opening response, verbal communication, and motor movement. The total of GCS scoring is based on a 15-point scale for estimating and categorizing the outcome of a TBI which is comprised of 3 scales i.e. eye opening responses 4, verbal response 5 and motor responses 6 points, respectively.

The other metric was formulated by US Department of Veterans' affairs and Defense on assessing the duration of loss of consciousness (LOC). A loss of consciousness of ≤ 30 minutes and a GCS of 13 to 15 is referred to as mild. The possibility of headaches, confusion, and memory loss is common in the mild brain injury though it may take days to months for these symptoms to appear.
Moderate is 9 to 12 and is rated on a loss of consciousness for greater than 30 minutes with physical and cognitive impairments which may resolve with rehabilitation.
Severe is between 3 and 8 and loss of consciousness takes more than 24 hours, which leaves the survivor in an unconscious state with no meaningful responses or voluntary activities for some time (Roebuck- Spencer & Sherer 2008:411).

Patients with severe TBI are in an extremely unstable condition and may require surgery for removal of epidural or subdural haematomas and repeated computed tomographic scans. They may need intracranial pressure monitoring, hyperosmolar agents to control increasing pressures and ventilator support (Bond, Draeger, Mandleco & Donnelly 2003:63). As severity levels increase, the range and extent of possible long-term physical, cognitive and psychosocial impairments increase. Individuals with moderate-severe TBI often have generally high permanent motor and cognitive limitations that impact their ability to meet typical societal adult expectations (Jacobson, Westerberg & Lexell 2010:102; Anderson, Brown, Kewitt & Hoile 2010:325). Severity is also classified on the basis of duration of post traumatic amnesia (PTA) which refers to a state following TBI where the patient is responsive but acutely confused and disoriented (Sherer, Nakase-Thompson, Yablon & Gontkovsky 2005:896).

While numerous studies have found GCS scores, duration of LOC and length of post-traumatic amnesia (PTA) to be predictive of both acute outcomes and various aspects of long-term functioning following TBI, the latter including neuropsychological outcomes and personal independence, current classification of TBI severity, is not without flaws. According to Sherer, Struchen, Nakase-Thompson, Yablon and Gontkovsky (2005:48), there are no universally accepted criteria for determining TBI severity with the independent use of the aforementioned common indices resulting in sometimes incongruent severity level classifications within a given patient.

People who survive a traumatic brain injury and their families may go through years of physical, cognitive and emotional changes. Some of the lasting physical effects of a TBI can be seizures, blurred vision, fatigue, headaches, muscle control problems, sexual dysfunction, and trouble with balance and dizziness. There are also psychological impacts including behavioural and personality changes, cognitive changes and emotional changes. In terms of the behavioural and personality changes, impulsivity, anger outbursts and inappropriate social behaviour are common (Uomoto & Uomoto 2011:18), however, the behavioural and personality changes are less understood and less researched.

Research has been largely unequivocal in demonstrating that TBI has a substantial negative effect not only on the injured person but also upon the family members especially those fulfilling the role of primary caregivers (Donaldson & Kalra 2005:138). In addition to disruption in family emotional, interaction, roles and communication following the injury, studies have found clinically significant levels of psychological distress of family members (Testa et al 2006:575; Kreutzer 2009:203). Family caregivers have to embark on a parallel journey of coming to terms with a ‘new normal’ person as the person they once knew is forever changed due to the brain injury. For recovery to progress, TBI survivors and the family caregivers need to have an opportunity to learn about the condition.

In South Africa, there is a growing trend of people requiring family caregivers and those taking up the responsibility of caring for their family members, which may be due to the increase of communicable diseases like HIV/AIDS and non-communicable diseases like strokes and TBI. In the African culture taking your family member to a hospice and other related facilities for end of life care is seen as abandoning or giving up on him/her. It is, therefore, common practice to see adult children choose going to live with their parents when they are afflicted with a chronic and debilitating condition alternatively parents move to their children's homes to be their caregivers.

According to Whiteneck, Brooks, Mellick, Harrison-Felix, Terrill and Noble (2004:584), the assumption of a caregiving role for such patients presents challenges to the existing family system influenced by such factors as types of support provided, family resources, role changes and relationship patterns. To gain understanding of how families perform and are affected by their caregiver functions, it is necessary to review potential cognitive, physical and psychosocial effects and consequences of TBI to people.

Researchers have recognized that caregivers in the acute phase following a neurological event may be primarily concerned with their family members' survival and may not feel the physiological strain one's body is suffering (Falk-Kessler 2011:49; Benge, Caroselli, Reed & Zgalradic 2010:844).

It is suggested that caregiver fatigue and social isolation may arise in the later stages of recovery particularly if caregivers perceive that both they and their injured family members have been abandoned by healthcare providers, family and friends. In addition, the need for supervision and caregiving may frequently change in the first two years after the neurological event. The following are the consequences that the family caregivers meet with when they are caring for a TBI patient:

2.4 CONSEQUENCES OF TRAUMATIC BRAIN INJURY

2.4.1 Cognitive consequences

Cognitive consequences of TBI may include short and long-term memory loss, concentration deficits, expressive and receptive language problems, spatial disorientation, organizational problems, and impaired judgment. According to Anderson, Simpson, Morey, Mok, Gosling and Gillitt (2009:303), adult survivors of childhood TBI experience global impairment: poorer school performance, employment difficulties, poorer quality of life, and increased risk of mental health problems, for example, adult survivors of childhood TBI are 3.0 times less likely to finish high school and 2.3 times less likely to graduate from college, and 1.7 times more likely to be unemployed and 2.1 times less likely to be working in a skilled profession than the general population.

The number and severity of the cognitive symptoms exhibited by survivors have direct implications for the level of practical assistance required from family caregivers. Therefore, the greater the number of and more severe the symptoms survivors exhibit, the more assistance their caregivers must provide. The more assistance caregivers provide, the greater the burden they experience. The greater the burden caregivers experience, the less willing or able they are to provide care to the survivor (Lehana, Arango-Lasprilla, De los Reyes & Quijano 2012:88).

Additionally, adults with TBI often perceive increased environmental barriers to independence (Sendroy-Terrill, Whiteneck & Brooks 2010:209; Whiteneck et al 2004:73). Researchers who conducted a large cross-sectional study of TBI patients found that about 44% of individuals with TBI in the U.S. who drove prior to the injury resume driving; those who did not resume driving post-injury experienced less community integration (Rapport, Bryer & Hanks 2008:922). Results of another study of individuals with TBI 2 to 7 years post-injury revealed that only 29% were employed, as compared to 86% employed pre-injury.

2.4.2 Emotional and neuro-behavioural changes

Emotional consequences of TBI may include increased anxiety, altered mood states, impulsivity, agitation or violent behaviour, plus egocentricity and lack of empathy for others (Brain Injury Association of America 2001) and as caregivers recognize significant changes in their family member's personality and behaviour, family stress often increases (Bond et al 2003; Degeneffe 2004; Djikers 2004).

Many researches on neuro behavioural changes post-injury highlighted the estimates of agitated behaviours during the acute recovery stage among individuals with moderate-severe TBI as ranging from 11% to 96%. In the chronic recovery stage, agitation has been reported to be at 31% to 67%, and irritability or temper has been reported in 37% to 71% of individuals with moderate-severe TBI (Silver, Yudofsky & Anderson 2005:225). Hora and De Sousa (2005) studied 50 caregivers of individuals with varying degrees of head injury severity, who indicated that individuals with TBI exhibited symptoms of aggression, irritability, poor impulse control, self-centeredness, anxiety, and forgetfulness.

Baguley, Cooper and Felmingham (2006:43) assessed predictors and prevalence of aggressive behaviour in 228 individuals with moderate to severe TBI at 6, 24, and 60 months' post-discharge in Australia. The researchers reported that 25% of study participants were classified as "aggressive" at any given time point. Depression was the only significant predictor of aggressive behaviour at all time periods, followed by age at the time of injury.

If the survivor was young, the more aggressive the patient would be. Baguley et al (2006:45) concluded that aggression is a common, long-term issue post-TBI. According to Anderson et al (2009:932), individuals with TBI are approximately 3.0 times more likely to have mental health problems than the general population. They investigated depression among individuals with TBI and reported prevalence rates ranging between 25% and 65%.

Researchers have indicated that individuals with severe TBI (cerebral contusion/traumatic intracranial haemorrhage) are 4.0 times more likely than the general population to commit suicide. Teasdale and Engberg (2001:4) concluded that the greater risk among the more serious cases implicates additionally the physical, psychological, and social consequences of the injuries as directly contributing to the suicides.

Many individuals who have suffered a traumatic brain injury are of working age (Johanson & Tham 2006:60). As a result of the stage of their lives in which this injury occurs it could be argued that their worker roles become disrupted. This means that the meaning that they may attach to their worker roles may become altered as well. In a study conducted with people with mental illness, a lack of occupation and a lack of valued social roles such as the worker role were found to be a major barrier in their lives (Bryant, Craig & McKay 2005:109).

2.4.3 Physical impairment

Physical consequences of TBI may include seizure disorders, sensory impairments, muscle weakness or spasticity, balance disorders including lack of coordination, poor balance and difficulty in planning and carrying out movements and fatigue. Motor control problems can be of great concern to family members, who frequently see household items broken.

Other physical symptoms may include speech problems, such as receptive or expressive aphasia (difficulty in understanding speech or expressing thoughts) or trouble articulating words. As expected, these problems may interfere with spousal communication, leading to frustration and, at times, anger (Ghajar 2004:923). Davidson, Howe, Worrall, Linda, Hickson and Togher (2008:325) who researched and studied extensively the negative impact that these difficulties have on social interaction explain that for the person with aphasia, changes in language processing immediately impact on his or her daily communication and change the nature of communicative exchanges and the quality of interactions.

According to a study by Langlois et al (2006:275), TBI can lead to increased risk for other health conditions. Results from a population-based study by Horner, Ferguson, Selassie, Labbate, Kniele and Corrigan (2005:322) indicated that from 1 to 3 years post injury, compared with the general population, people with TBI are 1.8 times as likely to report binge drinking, 11 times as likely to develop epilepsy and 7.5 times as likely to die.

According to Selassie, McCarthy, Ferguson, Tian and Langlois (2005:258), new health problems associated with TBI may also arise in conjunction with the aging process. These include a 1.5 times increased risk of depression and a 2.3 and 4.5 times increased risk of Alzheimer’s disease associated with moderate and severe head injury, respectively. A study conducted by Marsh et al (1998) as quoted by Ergh, Rapport, Coleman and Hanks (2004:155), suggested that behavioural problems demonstrated by persons who had suffered TBIs are more likely to have a severely negative impact on their caregivers as well as on family functioning.

The cognitive, emotional and behavioural deficits following TBI are not only problematic for the injured individual but are likely to prove stressful and disruptive to their families as well (Mokhosi & Grieve 2006:303). The process of adjusting to the injured individual’s changed functioning can be facilitated by gaining an understanding of the nature of brain injury and its consequences. An important aspect of care management is ensuring that the patient has an appropriate support system to meet his/her care needs. Realistic expectations regarding the nature of the injury and the possible outcome are fundamental to the rehabilitation process.

Maintaining unrealistic expectations tend to delay the acceptance by the patients and their families of the likelihood that some degree of disability may be permanent. The incidence of neuro-trauma is high amongst young people and this places a considerable burden on society not only in terms of high economic costs but also in terms of the other effects of neuro-trauma on individuals and their families (World Health Organization

(WHO) Collaboration Centres for Neuro- trauma 1995 as quoted by Mokhosi & Grieve 2006:301).

The experience of sustaining a disability or chronic illness can come unexpectedly to the individuals and their families thereby soliciting coping mechanisms to handle the stress of a disability's onset. The families are faced with some of life's largest challenges and embarking on the caregiving experience leads to a variety of burdens not only for the care receiver but for the caregivers as well (Catherall 2004:26). The caregiver has to deal with negative behaviours of the care receiver like destruction to property, increased amount of activities of daily living (ADLs) that require assistance and time spent caregiving.

According to US Dept. of Health and Human Services (1996) as quoted in Langlois et al (2006:376), traumatic brain injury can result in long-term or lifelong cognitive, behavioural/emotional and physical consequences. As a result of these consequences, TBI is regarded as one of the most disabling injuries. Although similar to several other types of injuries, the percentage of injury-related productivity loss attributed to TBI is 14 times of that associated with spinal cord injury, another important disabling condition (Finkelstein et al 2006:12). Even mild TBI, including concussion, can cause long-term cognitive problems that affect a person's ability to perform daily activities of their lives and to return to work.

Taylor, Yeates, Wade, Drotar, Stancin and Minich (2003:15) reported that parental stress predicted more behaviour problems in the brain injured child and that more child behaviour problems in turn predicted poorer family outcome. Others have found that siblings are also negatively affected by a brother or sister with a traumatic brain injury. McMahon, Noll, Michaud and Johnson (2003:287) found a poorer outcome in the child with traumatic brain injury to be significantly correlated with lower self-esteem and more symptoms of depression in siblings. Swift, Taylor, Kaugars, Drotar, Yeates, Wade and Stancin (2003:28) found that behaviour problems in children with traumatic brain injury predicted both sibling relationship and sibling behaviour problems.

Given these findings it could be expected that families with a home dwelling brain injured patient are being followed up in such a way that serious problems can be traced in a timely way and targeted support can be offered. Because of the sudden nature of the onset of the communication disorders and subsequent changes in physical status, behaviour and communication patterns, family members are not afforded time to adapt to these changes and frequently the sudden onset of these difficulties may be overwhelming for them. Laroi (2003:176), Stewart and Riedel (2011:44) and Wallengren et al (2008:69) suggest that the therapy required by families who have been affected by brain injuries involves working toward actual change in the family's organisation, structure or communication patterns.

More recently, it has been recognized that the effect on the individual as well as the caregiver influences the health and wellbeing of both (Chronister & Chan 2006:190). A study by Kreutzer, Stejskal, Ketchum, Marwitz, Taylor and Menzel (2009:535) on caregivers have shown that caregiving a TBI has negative health consequences to family caregivers like depression which may proceed for a long time like two years though Ponsford's study (2010) stated that at five years this decreased slightly but was still high as compared with the general population.

Caregiving traditionally lies with the informal caregivers who include the immediate family, spouse or friends especially women as they have been known to be providers of care and nurturing to those in need and vulnerable. According to Davey and Scinovacz (2008:10), it used to be a norm that people are nursed by family members in their homes. This responsibility was taken over from nurses and doctors due to increased accessibility of healthcare services; increased costs in healthcare and privatisation of health.

Another problem is the shortage of nursing personnel in hospitals and thus lowered quality of health standards. The challenges that come with caregiving for a person with a disability such as TBI can result in the caregiver experiencing isolation especially when they do not get assistance they themselves need such as training, support, education and regular breaks (Lim & Zebrack 2004:15; Hanks, Rapport & Vangel 2007:43).

The unpredictability of TBI can mean that even when the patient has survived, it is at times difficult to foresee how far one will recover and how long the caregiver will have to continue with the role and how far. According to Ergh et al (2004:190) and Oddy et al (2003:259), caregivers of TBI patients may perceive this caregiving as stressful and demanding and this can affect the whole family including the person with TBI. Studies have shown that personality and emotional changes have more significant effects on relatives than physical changes do. Researchers, therefore, suggest that family needs related to the patient should be addressed as early as when the patient is still admitted for rehabilitation as this can help improve long-term outcomes for patients and families (Bond et al 2003:63).

Concerns that plague family caregivers after a loved one sustains a TBI include the severity of the injury; prognosis; cost of hospital care; implications for major change in the patient's life; implication for major change in the caregiver's life; cost of long-term care; patient's need for long-term material, emotional and social support; and the patient's need for around-the-clock support/supervision. As displayed above these concerns vary and can only be understood as falling into broad categories pertaining to emotional, financial, and psychosocial changes as a result of the onset of the TBI.

According to Carnes and Quin (2005:186), families may experience psychological distress, marital discord and poor family functioning immediately after the TBI and this may continue for years. Caregivers of patients with TBI may not only suffer consequences of TBI but also experience a variety of social and emotional strains including complicated grief and ambiguous loss. These researchers define complicated grief as when one experiences numbness, detachment from others and difficulty in accepting the death of a loved one which, in this case, is not a physical death, but the loss that goes with TBI, of a job, income and the family functioning that the individual may no longer be able to do. On ambiguous loss, Boss (2004:554) state that this is when the individual is physically present but psychologically absent influencing some of the reasons for the marriage breakdowns in TBI. Owing to the unique context and the dearth of research in this area, this literature review is specifically aimed at exploring whether the experiences of families who have a member with TBI in South Africa is in fact similar to those reported by family caregivers in developed countries.

Of particular importance in this study are the long-term consequences of TBI, because these will affect not only the functioning of the individual with TBI after the discharge from the hospital or rehabilitation facility, but also the entire family especially their primary caregivers. An exploration of some of the more typical sequelae may help demonstrate the impact of TBI on the family system.

Mokhosi and Grieve (2006:301) found that the lower the individual's score on measures used to quantify levels of consciousness and alertness, such as the Glasgow Coma scale or the duration of post-traumatic amnesia, the more severe will be the complications. The effects are unique to individuals varying according to the extent of severity, location of the injury and the health status during the time of injury (Dikmen, Machamer, Powell & Tempkin 2003:1449).

In a study reviewing caregiving by siblings reveal that the caregiving task is undertaken mainly by women and girls, so caregiving often becomes a gender issue and this is seen as a female task (Prigatano 2006:501). Though there are men who are involved in the caregiving role, they are a lesser but not insignificant number. The traditional gender norms of Black South African prescribe the caring function to women hence more women and girls are involved in providing caring. It is further argued that men and boys who provide care may be invisible and underreported because it is socially unacceptable for them to be family caregivers.

2.5 DEFINITION OF A FAMILY

Dallos and Draper (2003:09) define a family as a primary social agent for the promotion of health and well-being in individuals. Confining this description to a single definition will be very narrow since the view of what constitutes a family has changed over the years, within different communities, societies, cultures and traditions. However, the above researchers suggest that some accounts from research used to capture the aspects of family life use two different approaches. The first approach is based on the view that some family members appear to make autonomous decisions about their lives. The second follows a suggestion that family life is characterized by repetitive, predictable patterns of actions, and when family members are faced with difficulties and challenges, they find ways of managing their challenges as they proceed through their developmental cycle.

The abovementioned explanation attempts to demonstrate two propositions about family life, suggesting that the outcome of family reaction to crisis or trauma is directly related to the family's interactive patterns of their daily lives. The family is a basic source of security and support as well as a springboard for physical, emotional, cognitive, moral, social and spiritual development in all societies. However, according to Donald, Lazarus and Lolwana (2002:246-249), this has not always been the case in Africa, especially South Africa because according to them family development in this country has been severely disturbed by westernization, urbanization, migrant labour, occupancy laws and other forms of discrimination that have further contributed to the disruption of many South African families.

Donald et al (2002:246) further add that the development of families in South Africa has also been affected by the prevalent socioeconomic challenges such as poverty, unemployment and the HIV/AIDS pandemic. Their description of a family leverages on the notion that it is a grouping that is usually created from an initial union of two people who first become parents of children and later grandparents running into generations, within the same homestead, held by a unique interpersonal system and, most significantly, their approach to family description rests in the view that a family is the main vehicle that transmits broader community and social values.

2.5.1 Impact of family caregiving

Pallathyil (2006:11) states that caregiving always impacts on the life of the caregiver in that those who are involved in the caregiving role always experience profound and wide-ranging changes in their lives. He further argues that the family caregivers are the cornerstone in the support of people living with TBI and refers to them as unsung heroes. According to Grant (2003:97), families have been the bedrocks of care for centuries and this has been a symbol of their natural love and altruism. Despite the importance of family caregivers, their contribution in caregiving is virtually invisible yet a crucial component following the onset of TBI in a family.

According to Goodhead and MacDonald (2007:14), caregiving arises out of a relationship with the care recipient in response to the need for support. This is greater than normally expected owing to the impairment in functioning. They further argue that caregiving is relatively invisible since it often emerges outside any formal agreement.

Family members most often assume the caregiving responsibilities for individuals with TBI, and may include many people such as parents, spouses, partners, siblings, adult children and grandparents (Ramkumar & Elliot 2010:105). Knowledge regarding the demands experienced by the family members, factors that buffer these demands and the family member’s quality of life outcomes is needed to better understand the phenomenon of family caregiving in the TBI population.

It is with this in mind that the researcher seeks to understand the experiences of family caregivers of TBI patients in order to provide a deeper understanding of the challenges they face and the efforts they make to cope with them. The lack of time to devote to self-care and preventive health behaviours on account of caregiving demands may contribute to long-term negative health outcomes for caregivers in addition to the direct effects of objective burdens and depression (Vittaliano, Young & Zhang 2004:16).

In a study by Rowe and Koloski (2007:6) caregivers reported to spend a lot of their time doing caregiving activities which often infringes on their time for other life activities. Some get restricted in their socialization as a result of caregiving, which has been identified as a critical cause of depression among caregivers (Bookwala, Yee & Schulz 2003:139).

There is very little published research that takes a systematic approach toward describing family caregiver roles and experiences after they have been in the caregiving role for several years but the studies of caregiver-related stress have made the researcher to recognise that TBI survivors' behavioural problems outweigh their physical disabilities in terms of the burden caused to caregivers. Some studies have been done on caregiving of patients with chronic conditions like stroke and Alzheimer but there is limited attention towards family caregivers of traumatic brain injuries survivors.

The impaired behavioural functions of the TBI patient can result in tremendous stress, fatigue and frustration in the family caregivers as they struggle to deal with the patient's constant demands for their time and attention, embarrassing behaviour in social situations, uncontrollable anger or violence, paranoia, struggles for control and emotional dependency.

Family caregivers may feel helpless against these overwhelming emotional responses and suffer their own erosion of self-esteem, guilt and feelings of inadequacy. Without a proper understanding of brain injury, family members may initially respond by treating the patient as they did prior to her/his injury, rather than recognizing that the changes are a permanent part of who that person now is.

According to the National Family Caregiver Association (NFCA), family caregiving has been defined as unpaid assistance by the family for physical and/or emotional need of another person. Family members take on caregiver roles because of love, obligation, or a sense of duty to the individual without expecting any remuneration for such services (Leske & Jiricka 2008:286). Family members may not participate at the same level as caregivers; some may assume roles of being primary caregivers or secondary caregivers. Primary caregivers which are normally the spouse or parent, have the chief responsibility for ensuring that the family member's care needs are met.

Research has been largely unequivocal in demonstrating that TBI has a substantive negative effect not only on the injured person but also upon family members especially those fulfilling the role of primary caregivers (McCullagh, Bridgstooke, Donaldson & Kalra 2005:2186).

In addition to the disruption in the family's emotional interaction, roles and communication following injury studies have found clinically significant levels of psychological distress of family members. Primary caregivers embark on a parallel journey of coming to terms with a new normal as the person they once knew is forever changed due to the brain injury.

For recovery to progress both the survivor and the primary caregiver alike have to have an opportunity to learn about TBI.

Other family members may perform secondary caregiver roles where they will ensure provision of other forms of support whether financial or emotional. These voluntary services provided by the families cause the government to save a lot of money because caregiving of TBI survivors takes a long time if not lifetime.

The family caregiver’s role can be broad and during the initial period of injury may be primarily to function as a surrogate decision maker but as time goes on activities range from helping with activities of daily living, such as meal preparation, showering, and getting dressed, to assistance with rehabilitation activities, such as advocacy and cognitive therapy. Additional caregiving duties related to providing direct hands-on care and financial support may become the responsibility of family members as the TBI victim progresses through the healthcare system.

Inattention to the needs of family caregivers may result in diminished caregiver health, reduction in caregiving ability, and increased utilization of formal healthcare services for both the caregiver and the care recipient. Meeting the needs of caregivers throughout their healthcare journeys is essential given the fact that successful social integration of adults with TBI is dependent on the conditions they experience when they return to the community (Rotondi et al 2007).

Traumatic brain injury can be one of the most disruptive and devastating events that can happen to families. With nine out of every 10 being discharged home, much of the care giving responsibility of care giving is left to family members. It can produce a wide and varied list of family and caregiver need, involving many hours of work and attention (Kreutzer, Stejskal, Ketchum, Marwitz, Taylor & Menzel 2009:535).

Furthermore, many of these additional duties are unknown to friends, family and colleagues as the survivor may show no physical evidence of their injury (Chamberlain 2006). The list of survivor, family and caregiver needs are varied due to the variability of the TBI. Depending on the needs of the survivor a parent, partner, children, or siblings may need to assist with bathing, feeding, meal preparation, or monitoring medications.

2.5.2 Family relationships in TBI

The onset of disability when one acquires traumatic brain injury can create unanticipated caregiving demands for families often due to the lack of available public supportive services available to persons with chronic disabilities and illnesses (Degeneffe, Boot, Kuehne, Kuraishi, Maristela, Noyes, Price, Stooten & Will 2006:43). As explained, families with parents, siblings, children or spouses/partners with disabilities can experience many stress related conditions e.g. depression and anxiety when they do not possess the necessary financial support and coping resources to effectively manage these demands (Degeneffe & Olney 2010:1416).

According to Robinson, Fortinsky, Klappinger, Shugrue and Porter (2009:1), family caregivers demonstrate high levels of psychological distress and depression; increased rates of physiological illnesses; lowered rates of engaging in preventive health behaviours; disruptions in their employment places and personal, financial and social problems. Arno (2002:16) concurs with Robinson et al that the physical impact of care can lead to long-term care needs for the caregiver. For instance, they could suffer from coronary heart disease and other health effects like elevated blood pressure, uncontrollable hypertension, poor immune functioning and an increased risk of mortality.

Some studies have shown that the relationships most affected by neurogenic communication difficulties are the ones between the injured individual and immediate family members (Boschen, Gargaro, Gan, Gerber & Brandys 2007:19). This may be due to the increase in demand placed on the family member as caregiver as well as conversational partner.

In a study conducted in Botswana, it was reported that 85% of family caregivers indicated disappointments as far as healthcare professionals were concerned because they were not receiving any psychological support from them (Kángethe 2009:116). This had a negative bearing on caregiving productivity and coping in general for caregivers. Hai (2004:23) reports that the health of older caregivers has deteriorated as a result of the physical and emotional stress of assisting their children some believing that their young ones have been bewitched. These beliefs impact negatively on their health and health seeking behaviours as the caregivers initially deny the change in the person’s health so may seek treatment very late.

2.5.3 Relationships of siblings

Like other family members, siblings are also often profoundly impacted, both negatively and positively, in their relationship to a person with a neurological disability. This is due to both the nature of the sibling bond as well as to how siblings relate to each other following disability. Sibling relationships are not subject to individual choice as they start from birth and continue until death, and may symbolically last even after the death of one of the siblings. Except for adoption, siblings derive from the same genetic pool and possess common cultural and environmental characteristics.

The strength of the sibling bond is expressed by the roles that siblings play as caregivers to their brothers and sisters with disabilities. Research by Sambuco, Brookes and Suncica (2008:8) on effects of TBI on siblings found out that siblings continue to maintain emotional ties and provide caregiving support throughout adulthood. Further, many adult siblings of persons with disabilities expect they will continue their roles as caregivers, especially when parents are no longer able to serve in this role and they assume this role from their own initiative as well as in response to family expectations.

2.6 FAMILY SYSTEMS THEORETICAL FRAMEWORK

The family systems theory is a descendent of general systems theory. A biologist, Von Bertalanffy (1950) in Friedman (2003:154), is credited with developing the first general systems theory which is an organizational theory that explains how each discreet variable affects the whole and how the whole affects each part. He suggested that principles can be applied to groups of phenomena that he coined as systems (Friedman 2003:152). Von Bertalanffy (1968:30) argued that systems are a set of interrelated elements but that each of the elements is distinct from the environment in which it is embedded.

General systems theory attempts to integrate and create wholes out of parts as a science of wholeness. Its principles are based on observation that nature is organized in the patterns of complexity and comprehensiveness. These larger wholes having unique characteristics that cannot be identified or accessed through the analysis of its component parts (Von Bertalanffy 1968:32).

The family systems theory is defined as a goal-directed unit made up of interdependent, interacting parts that endure over a period of time (Friedman 2003:154). This theory directs our attention towards the relationships and relationship issues between individuals. Its parts being in mutual interaction or recursively related, therefore, each part effects and is affected by the other parts of the system. Living systems such as families exchange information with their environment and govern themselves through implicit rules that are specific to their system.

The family is then viewed as being in a continual state of change given that the family will always be interacting with its environment. Hanna and Brown (2004:78) view families as units of a larger system (society) in which they belong, and they believe that they do not live in isolation.

This view confirms systemic thinking, where the family is perceived as a unit which functions through an internal organization of its sub-systems (couples, parents, siblings). Hanna and Brown assert that, when the functioning of the family's sub-systems breaks down, qualities such as leadership, harmony and balance are compromised. As a consequence, the ability to manage the crisis or stressor becomes negatively affected (Berry & Hardman 2008:27).

According to Friedman (2003:155), to understand the individual we must understand the family system, family's organizational pattern, family's ethnic and cultural background and the individual's environment. People cannot be understood in isolation from the family and environment of which they are coming from and focus should be placed on how they relate to one another within the system.

In a family as a system, everybody operates and functions according to set norms and principles and ones' behaviour is shaped and constrained by the relationships and the family contexts one has within the family system. Relationships in a family run in different ways between, for example, father and mother; child one and child two; extended family members, their interactions are numerous and the system develops over their life cycle (Verhaeghe et al 2005:1005).

As the family gets a crisis situation in their life as a collective, interactions occur triggering or affecting others and the cycle develops and evolves. The patient may be affected psychologically, socially and physically but the people in his immediate social context are also affected emotionally, behaviourally and cognitively. They have to change their day to day routines and plan for the future as they are thrown off their familiar paths and have difficulty finding their way back to normality (Meyerstein 2005:207).

While the detour has different meanings for the individual family members, sustaining one's sanity and preserving one's identity in the face of illness is a challenge. They fall into despair but are required to make meaning of adversity. In the context of chronic illness an exacerbation of the illness frequently elicits an anxious response from the caregiver. Her tension threatens the stability of the family system, for example, if it is the child who is a patient, stress may be displaced to the father who then withdraws and fails to give support. This action or lack of it provides positive feedback which can push the family into disequilibrium. If he responds with understanding and affection which is negative feedback, the threat is likely to be resisted and equilibrium restored and stability is maintained (Friedman 2003:157).

When families experience stress, such as when a family member is diagnosed with chronic illness, the homeostasis of the system is interrupted as the forces of togetherness and individuality may come in conflict. The family as a unique system always strives for togetherness which promotes closeness and sense of responsibility for each other.

Simultaneously each member of the family strives for individuality (self-differentiation) by attempting to achieve one's personal goals and responsibilities but when there is such a crisis as TBI, members of the family have to forfeit their personal goals to attend to the sick in terms of patient's medical regimen, continual hospitalizations and home life. In this way the goal of togetherness (interdependence) is achieved but at the expense of personal individuality.

The concept of interdependence is maintained within the family system in that family members strive to keep their stresses within the family and not disclose to other people like in community services. This is done to keep family problems within the family boundaries.

Due to the interdependent nature of the members within the family system, an impairment of one member such as suffering TBI, has a vast impact on other members within the system.

Members of the family are placed in a paradoxical position in which they have to maintain focus on the present and the future simultaneously whilst mastering practical and emotional tasks required of their immediate situation, all while charting a course of action for dealing with the complexities and uncertainties of their problem in an unknown future, thus creating difficulty for families trying to accomplish many simultaneous tasks.

For the purpose of providing a lens for treating family caregivers and the family it is best to place the unfolding chronic condition in a systems model that will integrate three evolutionary threads of the sick individual, the family and belief systems which includes the cultural background and the community one comes from.

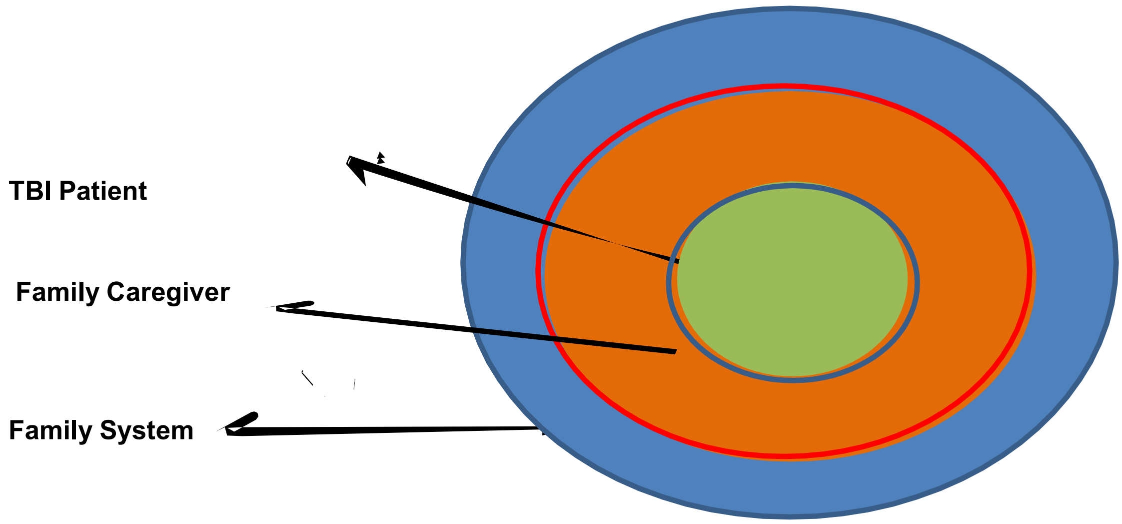

Figure 2.1 The family systems
(Rolland 1999:243)

Coping styles will vary for each family member and generally range from active and concerned to involvement towards the impaired individual to emotional detachment and distancing. The acceptance of the situation as well as the impaired individual also varies among the members. During this process family role are redefined and this proves to be a strenuous time for all involved.

According to Patterson and Staton (2009:149), the family resources and coping behaviours are viewed as the family protectors and in order for the families to accomplish a sense of equilibrium they have to perceive and ascribe meaning to the stressors they experience and the resources they have available to cope with the stressors. The family coping behaviours affect systems boundaries by two concepts known as engulfment and boundary setting which should be viewed in a continuum

Due to the challenges of chronic condition the caregiver may have mixed responses and at times shift from one end of the continuum to the other. Engulfment occurs when the caregiver subordinates her needs and activities to that of the patient. One gets so involved that the psychological suffering of the patient becomes entwined with the caregiver's and on boundary setting there is a psychological distance between the caregiver and the patient.

The family needs to be conceptualized as a social unit embedded in a context of other such units, from health services to communities and society. Systems theory moves beyond individualistic orientation, acknowledging the important role the family plays in the maintenance of health and reaction to illness and thus provides an appropriate framework to work from when conceptualizing the effects of TBI on the family.

King (1995) was among the first people to utilize systems thinking in nursing. In her systems framework which consists of three dynamic systems the personal, interpersonal and social systems for nursing, King views family members as complex subsystems who are in constant interaction with the environment. In this study the concept family does not refer to blood relatives only but to all significant 'others' of the patient.

Healthcare systems are open and professional healthcare providers are subsystems constantly interacting with the family members including the ones with chronic conditions to maintain their health as the goal of nursing action is to help individuals and groups to maintain health.

This approach emphasizes the complex family interactions between personal, interpersonal and social systems. The personal system is made up of individuals whose perception of self, body image and space, influences the way they respond to their environment, objects and events in life.
The interpersonal system is comprised of groups of healthcare providers, patients and family caregivers who have to interact and support each other. In this subsystem part of the interaction is the exchange of information in order to ensure an acceptable level of care. The social system is being composed of community as a whole, social organizations and healthcare delivery. Community members form links with each other. Change in the larger system may cause repercussions in the subsystems. When health programs are eliminated or reduced services by healthcare providers are limited, access to healthcare is reduced and families may be denied the care needed.

Family systems framework is based on the common understanding of concepts of interaction, empathy, transaction, goal attainment, perception, coping and health as essential components of nursing. According to systems theory, patients with chronic illnesses, as it is in TBI patients, are deinstitutionalized to provide more humane and less restrictive care by shifting the focus of care from large cold institutions to community settings.

Deinstitutionalization was grounded on the belief that all things being equal people fare better in the community than in a restrictive institutional setting. Regrettably this initiative failed such that persons end up being dependent on their families for care.

The impact of a chronic illness is not limited to the affected individual; the family of the affected person may be called to play a major role in the care of their ill member (Catalano, Kim, Ditchman, Shin, Lee & Chan 2010:57). Many families take this awesome caregiving role not in lieu of, but in lack of acceptable community alternatives. An understanding of the experiences and perspectives of families caring for young members is necessary and this investigation is appropriately undertaken by the discipline of nursing.

Nursing seeks to address itself to the human responses of both clients and their families. Individuals respond to their own actual or potential health problems and families may be responding to the health problems of one of their members. Such a focus recognizes the interaction and interdependence of members of a family unit. Family members become stressed and need coping skills, as illness of one member of a family will inevitably affect the rest of the family. While caring for chronically ill patients at home, the family members are required to adjust either positively or negatively to various constraints. Stressors like inadequate financial resources can have a negative impact on caregiving.

In order to maximize the capacity of the family's belief system to adapt to illness demands, whilst protecting the integrity of its most enduring values, an approach must be employed that identifies aspects of illness that challenge family life, as well as those aspects of family life that are most affected by chronic disorders. It is suggested that practitioners should always review the effect of illness on the family and help the family mobilize its pre-existing resources (McCullagh, Brigstoke, Donaldson, Kalral 2005:2186).

Patients suffering from TBI are usually young people who are in the process of starting their own families or who are starting their careers and beginning to gain independence. They may reject interference by family or significant others. Coping behaviours as they relate to family boundaries can be understood by one's behaviour and may be judged based on one's educational, cultural and ethnic context.

According to South African statistics estimates are that 70% of Blacks are functionally illiterate and are not informed of the prevalent conditions and this has implications for their understanding phenomena that affect their livelihoods. In some instances, the medical information provided is perceived as ambiguous and can lead to further confusion. Because of their misinformation families may not be aware of the chronicity of traumatic brain injury and its consequences to the family until they are faced with the problem. In addition, family members often do not realize that the entire family system may experience on-going stress associated with the psychosocial, financial and caretaking issues resulting from the injury (Mensah 2008:697).

Patients and families informed of the likely outcome of the brain injury at an early stage generally show proof of better social adjustment, with the disabilities or impairments being accepted and appropriate adaptations being made. The chronicity of the traumatic brain injury may also affect the caregivers' cultural and religious belief systems. If they perceive the injury as a way of punishment by God, they may have difficulty in coping but if they perceive it on a positive perspective as that there is no family without a person with a physical disability then their coping may be positive (Mokhosi & Grieve 2006:308).

According to the Department of Environmental Affairs and Tourism (2003), the majority of South African population live in rural areas. An increasing number of people live in urban areas because of the poverty of the rural areas. Very large numbers of people migrate, often illegally, to South Africa from other African countries, in search of employment and political asylum. In rural areas, there is little opportunity for employment, and if there is, it is usually informal.

The most common solution for families is to allow the adults of employable age to leave the traditional rural home, and seek employment in the towns. The children are left in the care of the extended family, usually the elderly, and most often the grandmother. She then takes care of many children, and depends on her children to send money, food and clothing home from the towns. This means that if a crisis of TBI occurs the grandmother or elderly person will be the one to nurse the patient, increasing more burdens on the person.

Every family system develops its own equilibrium and a means of coping in order to deal with the family upheaval. If one refuses treatment, for instance, caregivers may be forced to either forcing the individual sufferer or giving up thus disrupting the family cohesion. This means that the affected family should find other ways of maintaining equilibrium. A family crisis arises when the means of coping fall short of achieving a new equilibrium (Cope & Wolfan in Verhaeghe et al 2005:1005).

When a family member suffers TBI each individual in the family is affected adversely because TBI constitutes a major violation and a challenge to the family homeostasis. TBI not only has direct effects on patients physically, psychologically, emotionally and socially but also affects caregivers and other members of the family causing a different degree of permanent upheaval to the family system (Verhaeghe et al 2005:1005; Khiewchaum, Thosingha, Chayaput & Utriyaprasit 2011:128).

TBI often drastically increases family burden and can result in long-term family dysfunction. Depending on the severity of the injury, the presence of these changes may be either subtle or obvious. These changes cause problems of varying complexity for the individual concerned and for the social entourage. It demands that all individuals within the entire family as a system adapt to the condition, develop new patterns of living in order to achieve a balance in the altered situation. If the family becomes stuck in a specific stage growth is impossible and it is impossible to complete the cycle of development (Connor, Walker, Modi, Warlow 2007: 277).

Healthcare providers are encouraged to not only focus on the patient but on the family and significant others within the patients' environment. In the family nursing care strategy, which stresses that individuals should be nursed in relation to their family, the health status of the client is in the foreground but in the background is the family system or other members of the society in their context as caregivers or resources.

In order to be able to provide competent care the nurse needs to assess family realms like interaction, adaptation and coping strategies, the developmental processes that may affect the individual's health status and the outcome of interventions. To influence the ailing member to make a permanent lifestyle change, they need to coordinate their actions and possibly obtain outside social support (Gallant, Spitze & Grove 2010:23).

According to Friedman (2003:160), nurses need to be aware and involved in the effects of illness on human relationships central to the patient's wellbeing. They should not focus their care on the responsibilities or on the success of treatment such that they do not see the disintegration of personality and social relationships that make the individual. They should take note of the structures that build one's coping. Nurses hold a unique position among healthcare professionals in terms of prolonged proximity to patients during a stay in hospital or while a person with a long-term health problem is being cared for at home.

Though nursing has moved away from task orientation to a holistic view of patients as whole people, with a life beyond their illness experience but so far nursing has failed to address the needs of the families whose lives may be irrevocably changed by the chronic illness of one member (Levine, Halper, Peist, Gould 2010:116). The psychosocial strains on a family with a member suffering a chronic or life threatening condition can rival the physical strains on a patient. A study by Yeates, Swift, Taylor, Wade, Drotar, Stancin and Minich (2004:412) on relationship of family functioning and performance in children with TBI discovered that TBI sufferers from stable family environments fared better in both short and long-term when compared to those residing in families with limited resources or significant family turmoil. When there is a sudden occurrence of traumatic brain injury this calls for the system to use ways of adapting to change which is crisis management.

Family systems theory, in expanding the clinical focus from that of the individual to that of interconnected systems, allows the therapist greater access to resources within and connected to the family system (Becvar & Becvar 2009:390). This may then be used to assist the family system in moving towards greater functionality despite, as in the case of this study, the consequences of the neurological event.

After the occurrence of a neurological event or the diagnosis of an illness families are placed in a paradoxical position in which they have to maintain focus on the present and the future simultaneously whilst mastering the and emotional tasks required of their immediate situation, all while charting a course for dealing with the complexities and uncertainties of their problem in an unknown future.

A systems approach of care assists nurses to understand the dynamics of interaction, norms and values of the family. This approach provides insight into family interactions, expectations and adaptations to the needs of the ill member. A systems approach explains the complex client environment interaction and facilitates the assessment and analysis of clients and their relationship in a dynamic environment.

In facilitating the accomplishment of the task of dealing with a chronic condition, the family and the healthcare therapists, it is best to utilize family systems model functioning which will examine the individual, family, the structure and functions of these systems and their relationship to each other thereby exploring how the family responds to their environment when there is stress. No theory as yet covers all these aspects in caregiving.

2.7 CONCLUSION

The literature review conducted for this study has confirmed that there is very few research studies conducted in South Africa that have investigated the experiences of family caregivers of traumatic brain injury patients. Whereas many studies have examined the long-term toll of coping with a family member's chronic condition, studies have not specifically examined the subjective burden and practical difficulties associated with caregiving of TBI patients. Most certainly the medical technology to save lives and to rehabilitate physical injury has made tremendous strides but addressing the long-term consequences of TBI on the survivor and the family caregivers remains unexplored or beyond the scope of most provided services. Research with TBI caregiver populations is needed to describe this population in terms of caregiver roles and family caregiving systems structure.

According to research studies done on trauma crisis, the unique situation in which families of TBI survivors and their family caregivers find themselves in become apparent. There are possible difficulties in adjustment, adaptation, redefinition of roles in the family and attaching meaning to the experiences and rearranging their belief systems.

The use of a systems theory in this study is in order to understand the situation that families of TBI survivors find themselves in. It is, therefore, very important to understand the nature of families in general and how families function as a unit. Systems theory describes how systems and families function and will be used as the lens with which to view this study.

Chapter two has discussed the literature pertinent to the problem that the researcher wants to study. Chapter three will discuss the research methodology that will be embarked on in order to get authentic results.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The chapter discusses the methodological framework and the design strategies underpinning this research study. In addition, the chapter discusses the research instruments, sampling strategy, data collection, analysis methods and ethical considerations while explaining the stages and processes involved in the study. The processes used to achieve rigour and trustworthiness of the research methods are also discussed in this chapter.

3.2 PURPOSE OF THE STUDY

The purpose of this study was to develop a model of support for traumatic brain injury primary family caregivers.

The objectives of the study were to

- Explore and describe the unique experiences of family caregivers of individuals suffering from TBI following discharge from hospital rehabilitation.
- Identify and describe challenges experienced by family caregivers who care for TBI patients following discharge from hospital rehabilitation.

3.3 RESEARCH SETTING

The selection of a suitable setting, which is also referred to as the area of study, is critical for the study to be put into context. According to Polit and Beck (2012:57), the ideal research setting is where entry is possible, there is higher probability of rich mix of processes, people and interaction structures that may be part of the research question will be present.

Researchers also make decisions about where to conduct a study based on the nature of the research question and the type of information needed to address it.

According to Speziale, Streubert and Carpenter (2011:27), setting is a field at which the phenomenon of interest actually lives. Settings can be homes, health facility, community or sites selected by participants. Babbie and Mouton (2009:293) stress the importance of describing the environment under study so as to get the true reflection of the participants' experiences.

The study was conducted in the OR Tambo District of the Eastern Cape Province in South Africa. The researcher engaged on fieldwork taken in a naturalistic setting because she was interested in the contexts of people's lives and their experiences. The site consisted of the different communities within the O R Tambo district with homes of people living with adult TBI patients in order to get rich data from different participants who would be the primary family caregivers.

This area is the poorest in the province and in the country at large. It is characterized by poor infrastructure and a high level of illiteracy, poverty and unemployment and is peculiar for its high incidence of motor vehicle accidents, stick fights and factions.

Geographically O R Tambo District Municipality (ORTDM) is located in the eastern part of the Eastern Cape along the rugged borders of the Indian Ocean coastline in the Wild Coast, sharing its border with Alfred Nzo District municipality in the north, Ukhahlamba to the north west, Chris Hani to the west and Amathole to the southwest (ORTDM Integrated Development Plan Draft 2005/2006:1).

According to the 2011 statistics the population of O R Tambo district municipality was at 1365 million with an estimated growth rate of 1.47% per annum. The unemployment rate of the district has not been available to the researcher due to the fact that O R Tambo residents are mostly residing in rural areas engaged in farming. This may be due to the fact that ORTDM is mostly rural and it has regions that are inaccessible to compile an authentic statistics and some people prefer to do informal jobs.

3.4 RESEARCH APPROACH AND DESIGN

Research designs are plans that guide the arrangement of the condition for collection of data and analysis of data in a manner that aims to combine relevance to the research purpose. A research design is defined as a strategic framework for action that serves as a bridge between research questions and the execution or implementation of the research. Babbie and Mouton (2009:72) describe it as a plan or structured framework and instructions to be followed in addressing the research problem, its main function being to enable the researcher to anticipate what the appropriate research decisions should be so as to maximize the validity of the eventual results.

Holloway and Wheeler (2010:338) define research design as an overall plan of the research including methods and procedures for collecting, analyzing and interpreting data. Burns and Grove (2010:211) describe it as a blueprint for conducting the study that maximizes control over factors that could interfere with the validity of the findings; it guides researcher in planning or implementing the study in a way that is most likely to achieve the intended goal. The study followed a qualitative, exploratory, descriptive, contextual and interpretive approach

3.4.1 Qualitative research

According to Burns and Grove (2010:61), qualitative research means a systematic, subjective approach used to describe life experiences and give them meaning. It evolves from behavioural and social sciences as a method of understanding the unique dynamic holistic nature of human beings. The philosophy of qualitative research is interpretive, humanistic and naturalistic, concerned with understanding the meaning of social interactions by those involved (Burns & Grove 2010:356; Creswell 2009:113).

A qualitative approach was selected because of rich descriptive data that was collected through interaction with the participants which, because of its diversity, ensured that the researcher is able to formulate a model for caring for TBI patients. It was used to capture the family caregivers' narratives about their communications with the TBI patients in order to understand their experiences in their provision of care.

In this study, the qualitative research paradigm was chosen as an appropriate and relevant research approach that assisted the researcher in obtaining thick descriptions of the participating family caregivers' experiences in nursing traumatic brain injury sufferers, from their own natural settings. According to Sandelowski (2010:334), this design aims at providing a comprehensive summary of events in the everyday terms of those events. In order to accomplish this, the researcher captures information in a naturalistic setting of the participants.

Though considered pragmatic, interpretive and grounded in the lived experiences of people, Polit and Beck (2012:246) suggest that qualitative research should be sensitive to the social context in which data are collected and in order to produce good qualitative data the researcher should take cognizance of the flexibility in sampling and data collection.

Key features of qualitative design

Naturalism: Qualitative research is especially appropriate to the study of attitudes and behaviours best understood in their natural settings (Babbie & Mouton 2009:270). Qualitative researchers aim to describe and understand the nature of reality and behaviours through participants' eyes with careful and ongoing attention to context.

According to Polit and Beck (2012:15), reality is multiple and subjective rather a construction of individuals participating in the research. The researcher then took a position of relativism and did not want to manipulate the phenomenon of interest. The researcher went to do interviews in participants' homes so as to observe their behaviours as they interact in their natural settings. She also used audiotapes so as to capture all their interpretations of life as caregivers in totality.

Focus on process: The focus is on the process rather than the outcome. Qualitative research is suited to the study of social processes over time as they occur rather than having to reconstruct them in retrospect. There was a social problem which was a need for support, the population and the context where the phenomenon is occurring. The concern that caregivers of TBI patients might not be receiving the support and training that they require to create an environment of quality care was addressed taking into consideration the context (social and political) of their environment.

Insider (emic) perspective: The researcher attempts to view the world through the eyes (perspective) of the participants themselves. The researcher was the research instrument in order to capture the participants' culture (verbal and behavioural).

Describing and understanding (verstehen) rather than the explanation and prediction of human behaviour. Qualitative research is aimed at describing (thick description) the actions of the participants in great detail and attempting to understand these actions in terms of participants' own beliefs, history and context. It lends itself to describing phenomena in all their richness (Lo Biondo-Wood & Haber 2013:25). Qualitative research also brings to the fore the innate complexities and idiosyncrasies that form participants' experiences of their life-world. This is relevant to the proposed study since the focus here is to explore the participants' lived experiences of caring for their traumatic brain injured family members.

Contextualism: Qualitative research aims to understand the phenomenon within the concrete natural context in order to decrease generalizability. If one understands events against the background of the whole context and how such a context confers meaning to the events concerned that one can truly claim to understand the events (Babbie & Mouton 2009:272). The researcher wanted to identify the constructs of behaviours that are unique to the population in the socio-cultural setting that is not generalizable.

Inductive approach: The qualitative researcher begins with an immersion in the natural setting rather than beginning with a theory or hypothesis. The emphasis is on developing and building inductively based new interpretations and theories of first order descriptions of events, rather than approaching the social actors with deductively derived research hypothesis.

Subjectivity: In order to control any bias there has to be objectivity. In qualitative research objectivity is maintained by having the researcher as the instrument in the research process. Secondly, the researcher has to be close to the participants in order to generate legitimate and truthful insider descriptions.

Interpretive: Qualitative research formulates and interprets data based on the assumptions that human phenomena are fundamentally distinct from natural phenomena. Some of the critical differences refer to the inherent symbolic nature of human behaviour and the historicity of all human actions. In general, it implies that one aims at interpreting or understanding and reconstructing human behaviour rather than predicting it. The researcher develops a description of an individual setting, analyses data for themes and subthemes and make interpretations about its meaning personally and theoretically.

Holistic in nature: Holism refers to the concept that the whole is greater or different from the sum of its parts. Qualitative approach strives to bring all parts of the field together – person and situation, self and others, organism and environment, individual and communal. It assumes that all things are interconnected and that the organism and the environment co-regulate one another (Ginger 2007:2). In order to understand and describe a phenomenon the researcher has to understand an individual with his environment, the individual can exist only in an environmental field and is always a part of the environment.

A qualitative design was used because in terms of ontology there is a need for the emic perspective of the lived experiences of family caregivers of traumatic brain injured patients. Ontology encompasses the nature of the social world, existence, reality and the individual being (Finlay & Evans 2009:18). The needs, meaning they attach to their experiences and the environment the participants are living in have to be taken into perspective.

According to Brownell (2009:38), qualitative research focuses on the understanding of the individual as a unique and complex entity, leading to a descriptive and detailed presentation of findings which will assist in formulating a model of support for the family caregivers. The researcher did not formulate any assumptions and thus approached the study open-minded.

3.4.2 Exploratory design

Exploratory research investigates the full nature of the phenomenon, the manner in which it is manifested and the other factors to which it is related (Polit & Beck 2012:20). The main objective of explorative research is to identify key issues through interactive and inductive data collection and analysis (Creswell 2009:222). This design is typical when a researcher examines a new interest or when the subject of the study itself is relatively new. According to Barbie and Mouton (2009:79), exploratory research studies are quite valuable and essential whenever a researcher is breaking a new ground.

The researcher departs from a position of not knowing so she would seek to explore the topic and to provide a basic familiarity with that topic. The phenomenon of family caregivers of TBI is basically a new phenomenon in South Africa. The study was exploratory because the researcher explored the challenges that the family members experience in caring for a person who has been discharged from hospital after suffering from traumatic brain injury.

3.4.3 Descriptive design

A descriptive design is a mode of inquiry that includes an elaboration of the context of the situation as well as retrospective happenings and prospective plans surrounding the life event. According to Burns and Grove (2010:295), descriptive studies are conducted when one wants to provide an accurate portrayal of a phenomenon as a means of discovering new meaning and is designed to gain some information about the characteristics within a particular field of study. Descriptive research observes, describe and document aspects of a situation as it naturally occurs (Polit & Beck 2012:274). This means that after exploration of experiences of caregivers of TBI patients' thick descriptions of the challenges were given to provide the researcher with the opportunity to discover new meanings of what exists within the context of his/her study.

3.4.4 Contextual research

A contextual strategy is described as when phenomena are studied because of their intrinsic and immediate contextual significance. Contextual studies aim to portray events as they occur in their natural environment (Babbie & Mouton 2009:576). Holloway and Wheeler (2010:192) emphasize that the context is also associated with factors such as the environment, people, time and the historical background and therefore researchers should realize that the participants are grounded in their history and temporality. The study was contextual in design because its main aim was to provide an elaborate, dense description of the experiences of family caregivers for TBI patients after discharge from hospital rehabilitation in the rural OR Tambo district in the Eastern Cape.

3.4.5 Interpretive/constructivist paradigm

For the interpretivist inquirer, reality is not a fixed entity but rather a construction of the individuals participating in the research; reality exists within a context and many constructions are possible.

For this study the interpretive design was used so as to gain better understanding and meaning of the phenomenon under study from the descriptions given by the participants. The role of the researcher was to interpret the meanings of the experiences of family caregivers of TBI patients from the standpoint of their unique context.

3.5 RESEARCH METHODOLOGY

According to Babbie and Mouton (2009:647), research methodology explains the procedures that are employed in the process of implementing the research design or research plan as well as the underlying principles and assumptions that underlie their use. It is regarded as the epistemological home of an inquiry because it addresses the development, validation and evaluation of the research tools and the research process as a whole. The researcher ensured that this was achievable by using specific tasks of the research process such as seeking to know the population of the research, sampling method, data collection methods, data analysis and ethical considerations.

3.5.1 Target population

Polit and Beck (2012:337) and Botma, Greef and Mulaudzi (2010:124) define the target population as the entire aggregation of research participants who meet the designated set of criteria and are accessible to participate in the study. They further illustrate that the population is the aggregate or totality of those that conform to a set of specifications. Likewise, Cox (2013:1) describes the target population as the entire set of units for which the survey data are used to make inferences and those units for which the findings of the study are meant to generalize.

Individuals are selected as a unit of analysis when they possess an important characteristic that separates them from the others and that characteristic has an important implication for the study. However, the target population may not be manageable due to its size, location, numbers and other practical reasons. In this instance the accessible population becomes practical (Brink 2010:230).

The population for this research study comprised of all family members who were primary caregivers to patients living with traumatic brain injuries. These were obtained from the database of the trauma and intensive care units of hospitals in which the patients had been admitted and the prospective participants were written as next of kin. According to the information accessed there was an estimated one hundred and seventy-eight (178) patients who had suffered traumatic brain injury in the past two years.

The researcher phoned all those who met the criteria and personally invited them to participate in the study. Some relatives would respond by saying that the patient had since died or they had left the patients due to some relationship dynamics and so these were removed from the list and it ended up being 166. Of the patients that were accessed many of them were from the remote rural areas of OR Tambo district municipality, some of these areas are inaccessible in the Wild Coast.

The researcher communicated with the gatekeepers of the communities such as the chiefs, headmen and municipal councilors requesting to enter their communities. She created good rapport with them in order to get their cooperation. Establishing rapport in a research study is important to break boundaries between the researcher and the participants. Good rapport safeguards respect and trust on the researcher such that the participants openly and freely express themselves (Minichiello, Sullivan, Greenwood & Axford 2004:214). Through dialogue all involved in the study are able to account for their actions which may be established through interpersonal relations with the researcher.

In this study the researcher sought to understand and describe the experiences, values, actions, rich descriptions of concerns and challenges of family caregivers of TBI patients after discharge from hospital rehabilitation.

3.5.2 Sample and sampling technique

A sample is a subset of the population that is selected for a particular investigation (Polit & Beck 2012:131). It is a set of elements considered to be representative of the accessible or universal population. Sampling refers to the process of selecting a portion of the population that conforms to a designated set of specifications to be studied (Burns & Grove 2009:343). A non-probability, purposive sampling technique was used in this study.

- **Non-probability sampling**

A non-probability sampling method refers to that which is made up of subjects whose chances of selection are not known (Parahoo 2006:471). Selection is based on the availability or activity of the sample. The types of non-probability sampling include convenience sampling, quota sampling and purposive or judgmental sampling (Polit & Beck 2012:731).

The advantages of non- probability sampling are that it saves time and money as it takes advantage of respondents who are already available. According to Babbie and Mouton (2009:26), in non-probability sampling it is not possible to determine how representative the sample will be. This research study employed a non-probability purposive sampling strategy as the participants were selected based on their knowledge of the phenomenon.

- **A purposive sampling method**

In purposive research, the participants are selected based on their knowledge of the phenomenon and with the expectation that they will provide the needed information. Purposive research sampling enables the researcher to select participants that will most benefit the study as they provide the best data to understand the research problem. The researcher's knowledge of the topic, the population, its characteristics and the nature of the research purpose is sufficient to enable her to select cases deemed to be meeting the criteria.

As such purposive non-probability sampling of twenty (20) family caregivers was selected according to the sampling criteria, because the participants would offer useful manifestations of the phenomenon of interest and thereby respond to the research questions relevantly and shed light in the understanding of the phenomenon (Creswell 2005:185). Purposive research, therefore, limits the possibility of generalizing the results of the study beyond the specific sample.

All those chosen to participate were contacted telephonically or through writing. Primary family caregivers who were next of kin obtained from the database of brain injured individuals at the selected hospitals from 2012 to 2015, were contacted and requested to participate in the study. It was also indicated that other family members, also involved in the caregiving of the brain-injured individual could participate. In order to obtain a heterogeneous sample, no limitation was placed on the number of family members of a brain-injured individual; The family caregivers who were unwilling to participate were not coerced into participating and their names were deleted from the database.

Due to the rigorous and systematic nature of the data collection and analysis processes, qualitative research has been criticized as being labour intensive and time consuming. It has been suggested that between six to twelve interviews may be necessary to achieve the desired amount of data necessary for this method of analysis (Guest, Bunce & Johnson 2006:79). These authors have also cautioned that purposive samples need to be carefully selected as the number initially selected may not be enough if a selected group is relatively heterogeneous, the data quality is poor, and the domain of inquiry is diffuse and/or vague (Guest et al 2006:79).

In qualitative research smaller samples are necessitated as more data does not necessarily lead to more information and analyzing a large sample of information can be time consuming and often impractical

3.5.3 Sample size

The sample size is defined by Polit and Beck (2012:509) as the number of study participants to be included in a sample. Participants who met the eligibility criteria were included according to their availability and willingness to participate. For this study twenty family caregivers made the sample. In a non-probability sampling a sample is a relatively small unit that could provide particularly valuable information related to the research question under examination and where the purpose of the study is to generate themes (Strydom 2005:202).

In qualitative research sample size is not an issue as emergent cases are used until data saturation is reached. Data saturation is when participants being interviewed do not bring any new information but rather repeat what has already been mentioned.

Although the research may have a sample size, the researcher may decide to end data collection when data saturation occurs (Burns & Grove 2009:243). In this study the researcher collected data until she reached data saturation. The researcher stopped the interviews after nine participants had been interviewed because of saturation of data.

3.5.4 Inclusion criteria

The criteria used to select the participating families were based on three factors namely:

- The participants should be currently giving care to an adult patient who had been discharged from hospital rehabilitation after TBI in the past two years.
- Those able to articulate and willing to share their caregiving experiences with the researcher.
- Those willing to receive the researcher in their homes allow her to visit for observations during the in depth interviews.

3.5.5 Exclusion criteria would include:

- Family caregivers who were reluctant to participate
- Family caregivers with an experience of less than two years providing caregiving to an adult TBI patient

3.6 DATA COLLECTION

Data collection refers to the process whereby information is collected in order to achieve the aims of the study (Burns & Grove 2009:695). In this study, the researcher collected data from the family caregivers of patients with TBI post discharge from hospital rehabilitation in the OR Tambo District Municipality.

Experiences and challenges of family caregivers' regarding caring for their TBI patients were obtained within the framework of semi-structured interview. According to Babbie and Mouton (2009:289), semi-structured interviews are discovery oriented methods that are suitable for describing both the program and outcomes from the target audience or key stakeholders. The interviews comprised of one major question, **'What are your experiences of caring for a family member who has suffered traumatic brain injury'?** The interview schedule was used to probe the caregivers' experiences of caring for their patients following a neurological injury (see Annexure 4). The questions posed investigated how cognitive-communication difficulties had impacted on their communication within the family.

The researcher probed the caregivers' expectations regarding the life changes and plans for the future and on information they would have found useful in the acute stages of the neurological event and during rehabilitation. The questions were structured in such a way as to elicit information regarding any resources or services that had positively or negatively impacted on their caregiving experiences. The semi-structured interviews allowed participants time and opportunities to express their unique perceptions of their quality of life and the factors that may have affected their caregiving experiences. This meant having to explore the social context influences that could have influence in their lives.

3.6.1 Data collection instrument

Data collection is a process whereby information pertaining to a phenomenon is sourced through data collection instrument like interviews, questionnaires, artefacts, records, observations and field notes. For this research study the researcher was the sole investigator who interacted with the participants and thus was able to realize and holistically study all the realities of the family caregivers of TBI patients.

The researcher was the research instrument as she conducted face to face, semi-structured interviews.

Interviews refer to a dialogue between the researcher and the research participants with the purpose of eliciting the participants' perspectives or ideas on the phenomenon of interest (Holloway 2005:293). The information from the literature review was used to develop interview schedule for the study which would assist the researcher in the questioning of participants.

The researcher as the primary data collection instrument is a characteristic of a qualitative approach. The philosophical underpinnings of a qualitative paradigm obligate the researcher to accept self as part of the research (Speziale et al 2011:5). The following characteristics unique to human beings qualify them as human instruments:

- Responsiveness: one can sense and respond to all personal and environmental cues that may exist.
- Holistic: the human instrument can be able to grasp the whole phenomenon and its context in its entirety.
- Adaptability: the human instrument is capable of collecting data about the multiple factors happening at the same time.
- Clarification and summarizing: can be done whilst the human instrument is collecting data from the participants.

- Process immediacy: only human instrument has the ability to process data as soon as they become available.
- Opportunity to explore idiosyncrasy: atypical responses are explored and tested for validity.

3.6.2 Research question

Participants were asked a single question which was phrased according to the participants' understanding which was: **What are your experiences of caring for a family member who has suffered traumatic brain injury?** A follow-up question was introduced in relation to the experiences and challenges encountered by the participants when caring for TBI family members. As the aim of this study was to develop a model of support for traumatic brain injury family caregivers in order to increase their coping mechanisms when caring for a member with TBI, the participants' words and actions would be vital in developing an understanding of the family caregivers' experiences of caring for their family members. Field notes were taken during interviews to document the non-verbal communications, cues and contexts.

3.6.3 Pre-testing the data collection method

Pretesting of the data collection method is done as preparation for the major study to assist the researcher with an advance warning about where the main research project could fail, where research protocols may not be followed or whether the proposed methods or instruments are inappropriate or too complicated (Polit & Beck 2012:467). Pretesting was done on two family caregivers who met the eligibility criteria and who had granted permission to participate in the study. No changes were effected in the methodology after pretest and the findings of the interviews were included in the final discussions of the results.

3.6.4 Data collection process

Data collection started in May 2014 executed in three phases: preparatory phase, gaining entry and leaving the field.

- **Preparatory phase**

The preparatory phase included the gathering of adequate information about the investigation including the rigorous integration of the research method, preparing the interview guide and identifying the target population.

The researcher had to decide when and how to gain access to the hospital to get information of the prospective participants.

- **Gaining access to the field**

Initially the ethical clearance of the research proposal from Higher Degrees Committee of the Department of Health Studies, University of South Africa (UNISA); and then an ethical approval to conduct the study in the Eastern Cape's OR Tambo District from the Department of Health Eastern Cape was sought. Subsequent to those approvals, the researcher requested to use hospital records from the Chief Executive Officers of the identified referral and rural hospitals in order to identify the patients that could be followed. The researcher made an appointment to present herself in person to the chief executive officers and the nursing managers so as to gain credibility with the academic hospital management.

The researcher collected a list of traumatic brain injured patients referred from different rural hospitals in the OR Tambo district and compiled her own database from the year 2012 to 2015. Prospective participants were contacted telephonically, but some of the patients were identified to have died after discharge or after being transferred back to their prospective referral hospitals. Family caregivers of such patients were cancelled from the database.

- **Recruitment of participants**

Participants were recruited before data collection phase because appointments had to be made with them. Formal letters were written requesting the participants' permission to participate. The purpose of the study and need for interviews was thoroughly explained to them. They were expected to sign a consent form before commencing with the interviews, if they were agreeable to its contents which included being audiotaped. The researcher was conscious of the fact that she had recruited a large number of prospective participants but she was preparing in case some would withdraw because of unforeseen circumstances.

- **Leaving the field**

This stage marked the end of the enquiry which included the when and how of terminating the study as well as addressing the related ethical and emotional questions. The field was left when the researcher was satisfied that the data had maximally highlighted the experiences and explained the key concepts in the data, adequately addressed the objectives of the study and satisfactorily answered the research question.

This also meant that there was no new data forthcoming meaning that the study had reached data saturation. An understanding was made that the researcher could return to the participants for more information or more clarity if this was required.

3.7 ETHICAL CONSIDERATIONS

Polit and Beck (2008:170) and Van der Walt (2011:326) mention that in order to ensure a high standard of research ethical guidelines are to be set so as to direct the researchers. The researcher shall ensure that the three primary ethical principles on which standards of ethical conduct in research are based are maintained. These include the following:

- **Informed consent**

The researcher provided accurate and complete information in order for the participants to fully comprehend the investigation and consequently be able to reach a voluntary, thoroughly reasoned decision about possible participation (refer to Annexure 4). They were informed that:

- They were at liberty to withdraw from the investigation at any time while explaining the foreseeable consequences of withdrawing.
- Interviews would be audio taped and the reason thereof explained.
- They were not going to be remunerated for participating in the research study as their participation would benefit the society. The results of the study would be cause for change in the provision of health services for the TBI survivors.
- They would be expected to sign a consent form which would give accurate information on goals and process of the study, to confirm their willingness to participate.

- **Beneficence and non-maleficence**

Beneficence implies that the participants benefit from the study and non- maleficence means that the study does not cause the participants any physical or emotional harm (De Vos, Strydom, Fouché & Delport 2011:113). The researcher has an obligation of protecting participants from putting them in situations that are stressful and anxiety provoking.

This study had a potential of provoking psychological discomfort and creation of all sorts of emotions like anger and frustration because the researcher would be seeking to know their experiences, so patients were informed of the fact that they were free to withdraw when they were not feeling comfortable and all the vulnerable participants would be identified before the beginning of the interview. If the participants displayed signs of depression, then the researcher would organize debriefing sessions for them. They would also be afforded counselling services free of charge if and when there would be a need for that.

- **Confidentiality and anonymity**

Appropriate steps were followed to ensure that the rights of the participants were not violated in any way and the adherence to the ethics of research ensured. The researcher ensured participants of confidentiality and anonymity by making use of codes instead of their names. All the documents used for research were kept in a safe under lock and key, the information in these documents were used for research only and thereafter would be destroyed.

3.8 DATA ANALYSIS

Data analysis is the process of reviewing information that has been collected in a study and identifying areas of commonalities and differences in order to group this data into usable categories. Engaging in analysis involves researchers dwelling with their data, examining it and then progressively deepening their understanding as meanings come to light (Finlay & Evans 2009:145).

The audio tapes that were used during interviews were identified by the dates on which the interviews were done rather than the names of the participants. Data from the audio tapes were transcribed verbatim after the interviews when the researcher had completed conducting the interviews. Field notes that were written during the interviews were used to support the verbatim transcripts during data management.

Performing data analysis in qualitative research involves dismantling, segmenting and reassembling data to form meaningful findings in order to draw inferences (Boeije 2010:38). In qualitative research data analysis involves categorical and contextualizing strategies, which result in themes and include breaking down narrative data into smaller units, making connections, rearranging units and producing categories to facilitate better understanding (Teddlie & Tashakkori 2009:25; De Vos 2005:335). In this study data was organized according to topics.

Analysis of the data collected followed the steps mentioned below as highlighted by Tesch's method of analysis and began whilst interviews were still underway (Creswell 2009:192).

Phase 1: The first step was to collect the data. Audiotapes were used for this purpose. During this stage, the researcher familiarized herself with the data collected during interviews, listened to the audiotapes and transcribed the data verbatim. She also read, and re-read the data and noted down initial ideas. This constant comparative method was employed to identify emerging themes from interviews and various supporting data. The data was then clustered into categories and linked to identify different themes and concepts that emerged that are related to the addressing of the research question.

Phase 2: This is the stage of generating initial codes. During this phase, the researcher attached codes to the interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. The codes were collated into potential themes, gathering all the data relevant to each potential theme. Patterns of experience were listed from the transcribed conversations, which came from direct quotes or paraphrases of common ideas. The researcher also made use of quotations made by participants, selected them to validate the themes identified as family caregivers described their situations and feelings.

Phase 3: Themes review is done during this phase. The researcher identified all the data that related to the already classified patterns. All the tasks that fit under the specific pattern were identified and placed with the corresponding pattern. This is followed by combining and cataloguing related patterns into subthemes. Themes were then identified by bringing together components, fragments, ideas or experiences which were often meaningless when viewed in isolation and continue with analysis to refine the specifics of each theme and the overall story that the analysis tells.

Phase 4: This phase involved the selection of vivid, compelling, extract examples and the final analysis of selected extracts, relating back to the research question and literature so as to produce the final report. When reporting the findings, examples from the participants' verbatim statements were included so as to engage the reader in consensual

validation of the text. In order to avoid plagiarism and maintain scientific honesty the researcher gave an emic view of the phenomenon of caregiving.
An attempt was made to portray the views of the participants not those of the researcher and data collection continued until it reached saturation. The researcher maintained a high integrity by acknowledging the sources that were used.

3.8 RIGOUR AND TRUSTWORTHINESS OF THE STUDY

For the findings of any study to be accepted as credible and trustworthy, meticulous attention to the aspects of validity and reliability are very important. In this study Guba's model of trustworthiness of qualitative research was utilized to ensure its validity and reliability. Trustworthiness can be seen as a foundation of qualitative study because it ensures that empirical data that is believable is collected so that other researchers are able to confirm the validity of the findings (Lincoln & Guba 1985 as cited in Schurink, Fouché & De Vos 2011:419).

This model is based on four aspects of trustworthiness namely truth-value, applicability, consistency and neutrality. Truth-value is ensured by the application of credibility strategies, applicability is ensured by strategies of transferability, consistency is ensured by strategies of dependability and neutrality is ensured by the strategies of conformability.

According to De Vos (2005:48) and Milne and Oberle (2005:413), any worthwhile research study must be able to withstand rigorous scrutiny in the scientific world. The principles of trustworthiness will be described as follows:

- **Truth value**

This aspect of trustworthiness strives to establish confidence in the truth of the findings of an inquiry for the participants with which, and the context in which the inquiry was carried out (Lincoln & Guba 1985:290). Strategies of credibility were used in this study to ensure the truth value and means of ensuring credibility are discussed.

Strategies of credibility

The researcher ensured to highlight that there is compatibility between the constructed realities that exist in the minds of the participants and those that are attributed to them by triangulation and prolonged engagement (Bryman 2012:88). Credibility is a confidence in the truth or information as expressed by people within their environmental context (Leinenger & McFarland 2006:89) aimed at showing compatibility between the constructed realities that exist in the minds of participants and those that are attributed to them.

To ensure the credibility of this study, the researcher followed the following procedures as cited by Babbie and Mouton (2009:277) and Polit and Beck (2012:39) which are prolonged engagement, persistent observation, triangulation and member checking.

***Prolonged engagement*:** The researcher started by explicating her beliefs and knowledge about the research problem, her personal interest and pre-understanding of the problem were not denied but were made explicit at the beginning of data collection by keeping a personal log to describe her existing knowledge about the phenomenon of TBI. The researcher took time to prepare for the data collection in order to achieve the purpose of the study. The researcher started by building trust relationship with the participants by occasionally visiting them in their homes so that they could be acquainted to her.

The researcher conducted interviews herself to ensure data saturation and referential adequacy, for example, the use of audio tapes to document her findings. The research participants were given copies of the raw transcriptions of each individual interview. They were encouraged to review the transcripts and make any changes necessary to ensure accuracy. Minimal changes were made to the transcripts.

***Persistent observation*:** The researcher consistently pursued interpretations of the participants in different ways. During data collection the researcher took time to build trust with the participants and to clarify any misconceptions about t the research study. Field notes describing the environment in which the study was taking place were taken. Greef (2002:298) maintains that the field notes help researchers to remember and explore the process of the interview and is a written account of the things the researcher hears, sees, experiences and thinks about in the course of the interviewing. In this study, field notes were employed in the data analysis.

Triangulation: According to Babbie and Mouton (2009:274), triangulation is a plan that makes data to be believable and free from biases. By combining methods of qualitative investigations in the same study (descriptive, explorative and contextual) partially overcame the deficiencies that flow from one investigation. The researcher used literature review of different methodologies to make the study believable. Literature triangulation which includes background and rationale of the study was formulated from the different information sources. Author triangulation was ensured by the researcher working with the supervisor and her co supervisor.

Member checking: The researcher took the transcripts and analysed texts back to the participants to check whether what she had constructed from her data was actually what they had said (Babbie & Mouton 2009:276). The researcher gave transcripts to independent researchers for peer review to check the authenticity of data (Creswell & Clark 2007:91). Participants were given an opportunity to provide feedback regarding discrepancies between the reports and actual experiences. They were also promised to be given the opportunity to receive results of the study in writing.

The credibility of this study proved that the study had the quality of dependability, which implies that if it was to be repeated with the same or similar participants in the same or a similar context, its findings would be similar (Babbie & Mouton 2009:278). Credibility was ensured by an in-depth description showing complexities of the variables making sure that in the parameters of the setting of this study, the population and the theoretical framework underpinning this study is valid (De Vos 2005:346).

- **Applicability**

According to Polit and Beck (2012:539), applicability refers to the ability to generalise the findings of the study to larger populations or can be applied to other contexts, settings or groups. In this study, strategy to ensure applicability which is transferability was discussed.

Transferability: Refers to the extent to which the findings can be applied in other contexts or with other participants. No generalization was entertained as the population of this study was unique to the O R Tambo Municipality District. As suggested by Lincoln and Guba (1985) in Creswell (2009:113), a rich and thick explanation of research sites and characteristics of case organizations were provided to enhance transferability.

To ensure the transferability of this study, the researcher provided adequate information on the study process for replication such as the study purpose, objectives, recruitment and sampling strategies, data collection procedures and data analysis (Sandelowski 2010:334). She further explained in detail descriptions of data in context and reported them in sufficient detail and precision to allow judgments about transferability to be made by the reader (Babbie & Mouton 2009:277). The findings of this study are limited to the family caregivers of patients with TBI in the rural settings that the researcher included, however, other settings can be used in other communities with similar problems.

- **Consistency**

This criterion of trustworthiness considers the consistency of data by ensuring whether the findings would be consistent if the inquiry were replicated with the same participants or in similar context (Krefting 1991:216). This criterion is ensured by the application of strategy of dependability in the study and the strategy is discussed.

Dependability**.** According to Babbie and Mouton (2009:278) dependabiility refers to the degree to which the findings can be applied to other contexts and settings or with other groups. The auditors, in this case the supervisor and co supervisor, examined documentation of critical incidents, (interview notes, findings, interpretations and recommendations).

Dependability is parallel to reliability as conducted in quantitative research studies. According to Babbie and Mouton (2009:289) dependability as an enquiry must provide its audience with evidence that if it were to be repeated with the same or similar respondents in the same or similar context its findings would be similar. Dependability, as described by Sandelowski (2010:336), is a criterion used to judge the accuracy, completeness and accessibility of the research process.

The supervisors and copy editor for this researcher were used as auditors of the reviewed documents produced during the study. The supervisors also reviewed transcripts for analysis and an independent qualitative researcher was also used to review the transcripts.

- **Neutrality**

This refers to the degree to which the findings are a function solely of participants and the condition of the research, and not of other biases, motivations and perspectives (Lincoln & Guba 1985:291). In this study, neutrality was ensured by applying the strategy of conformability which include some of the criteria already discussed.

Conformability**.** According to Babbie and Mouton (2009:278), conformability is the degree to which the findings are the products of the focus of the inquiry and not the biases of the researcher. The researcher has to undertake an audit trail, that is, an adequate trail should be left to enable the auditor to determine if the conclusions, interpretations and recommendations can be traced to their sources and if they are supported by the enquiry.

To conduct such a trail, the following data was made available for audit i.e. raw data which was recorded in audiotapes, data reduction and analysis products, which are write-ups; field notes; summaries and condensed notes; data reconstruction and synthesis products, i.e. themes that were developed; findings; conclusions and a final report; material relating to intentions and depositions, i.e. inquiry proposals; personal notes and expectations; and instrument development information (Teddlie & Tashakkori 2009:297).

An independent qualitative nurse researcher was used as a reviewer of audiotapes and the focus of member checking helped the researcher in discovering omissions of comments and to verify placement of phrases into categories. The supervisors were also involved in the analysis and formulation of themes.

3.9 CONCLUSION

The chapter has outlined the research methodology that is to be followed in conducting this research study. It further outlined the population that was studied; the sampling procedure; the research setting; gaining access into the research setting; data collection and analysis procedures; and the ethical issues.

At the end of the chapter, rigour and trustworthiness of this research process and the methodological issues encountered have been described. The next chapter will be on the analysis of data and discussion of the analyzed data.

CHAPTER 4

DATA ANALYSIS, PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

4.1 INTRODUCTION

In this chapter, the findings of this study will be discussed, the purpose thereof being to present the full spectrum of experiences and challenges encountered by family caregivers of individuals with TBI. The objectives of this study were to:

- Explore and describe the unique experiences of family caregivers of individuals suffering from TBI following discharge from hospital
- Formulate a model of care for family caregivers who care for TBI patients following discharge from hospital rehabilitation.

The chapter begins by discussing the profile of the sample studied and its characteristics in order to better understand the nature of the findings. The sample profile was followed by the presentation of results and the discussions of the main trends and patterns in the data, with reference to the research objectives and questions.

4.2 BIOGRAPHIC DATA OF PARTICIPANTS

The participants' age ranged from 20 to 68 years. Only one participant was younger than 30 years of age. This indicates that family members are willing to take a caregiver role when they are older. When considering the psychosocial developmental stages of Erikson's stages of psychosocial development, the family caregivers who participated in this study belonged in the generativity versus stagnation stage of development. In generativity stage people display characteristics of concerning themselves about enriching other people and passing on their culture to the younger generation. They have a sense of productivity and accomplishment results.

The participants were all living in the rural areas of the OR Tambo district, which is the most underdeveloped area in the Eastern Cape., of the nine participants, four were caring for patients who had sustained TBIs in trauma related incidents like in fights or falls and five had been involved in motor vehicle accidents (MVA). Seven of the survivors of TBI had either been admitted to an ICU or high care units being intubated and ventilated for days and had experienced in-patient rehabilitative care during their stay in hospital.

The pathologies identified resulted in reported physical, cognitive and communicative difficulties, which decreased their independence and prohibited them from staying alone. The length of time from injury was varying from one year to three years, which means that this could give different perspectives on the experiences felt by the family caregivers and how the TBI had altered their lives.

As for the relationship of the participants to the patients, one of these nine participants was a grandmother, three were mothers, one a daughter and four were wives of the patients. The demographic data of the participants in the study is discussed in Table 4.1 in more detail.

Table 4.1 Demographic data of participants

Code	Relationship of caregiver to the patient	Age of caregiver	Marital status of caregiver	Gender of patient	Cause of injury
AA	Grandmother	≤68 years	Widowed	Male	Trauma
AB	Parents	61 and 65 years	Couple	Male	MVA
AC	Spouse	44 years	Married	Male	Fall
AD	Mother	63 years	Married	Female	Assault
AE	Daughter	24years	Single	Female	MVA
AF	Mother	60 years	Single	Male	MVA
AG	Spouse	34 years	Married	Male	MVA
AH	Spouse	62 years	Married	Male	MVA
AI	Spouse	53 years	Married	Male	MVA

4.3 DATA COLLECTION PROCESS

Data was collected by the researcher from the participants, through individual in-depth interviews. The participants were included in the interviews according to pre-determined eligibility criteria and their willingness to participate in the study as explained in Chapter 3 of this study. Upon receipt of permission to conduct the study, interviews were scheduled and conducted in the respective homes of the caregivers. The reason for doing interviews at the homes of the participants was to ensure their convenience and to observe their dynamics as they related to their experiences and challenges of caring for TBI patients in their natural settings.

The interviews were done for two weeks because of the distance between the participants' residence and the researcher's and the fact that in some cases the participants would not honour their appointments due to some other commitments that would crop up and because of unavailability of network in some communities they would not be able to communicate this to the researcher. An interview schedule was used as a guideline for conducting the interviews, so as to ensure uniformity and repeatability of this study.

The participants gave written consent following a thorough explanation of the purpose of the study and the contents of the consent form read out to them (refer to Annexure 4 for informed consent form). Though the participants were mostly illiterate they could all write their names. Permission to conduct the research study was received from the Department of Health, Eastern Cape Province (refer to Annexure 2).

The letters granting to the researcher for permission to conduct the study from the municipality together with the research ethical clearance certificate from the academic institution (refer to Annexures 1 and 3) were presented to the participants prior to data collection in order to demonstrate permission granted by the higher authorities. The participants were informed of the reason for the use of an audiotape as being that the researcher wanted to get all their responses recorded as they would help her during data analysis and they agreed to be audiotaped.

The researcher herself explained why the participant was chosen to participate in the study as being the fact that the participant was within a group that the researcher identified as her population and that through purposive sampling one got to be selected. The researcher then began the interviews with a welcoming statement which was as follows:

> "Welcome and thank you for availing yourself for this interview session. I am supposed to be doing the interviews in an international language which is English in order for me to be able to transcribe what you have said as verbatim as possible but if you are unable to speak English I will use Xhosa and interpret what you have said into English."

The duration of the interviews was approximately 45 and 50 minutes. Interviews were audio recorded, accurate field and reflective notes were made on each session and were kept for use during the data analysis process. One central question was asked. **"What are your experiences of being a family caregiver to a person with traumatic brain injury?"**

The interview question guided the participants through their experiences at the times of injury, hospitalization, rehabilitation and transition to home. The interviews were conducted using vernacular language which would be translated to English afterwards during data analysis. The question required them to reflect on how ideas about themselves and their lives were influenced by the described experiences, how they managed experiences, what they perceived as helpful, how they made sense of their experiences. Probing questions in relation to the responses from the participants then followed. The use of the interview guide assisted with the probing of questions: The questions that were used for the interview are attached as Annexure 5 (interview guide).

Nine interviews were conducted with nine participants who were all females though in one family the father was present during the interview and would pitch in when he felt he could add to what his partner was saying. The man who participated as a couple was more involved in assisting the woman caregiver as he put it, that he did not want to be an absent father. All the participants were from the poor rural background. The issue of absence of men as family caregivers is in line with Piot, Greener and Russell's (2007:4) and Ssengozi's (2009:339) assertion that women from poor backgrounds are usually the main caregivers in chronic conditions.

4.3.1 Challenges during interviews

The researcher encountered some challenges during the interviews from the participants, like:

- Reluctance to talk about their experiences: The participants were reluctant to talk about themselves as caregivers but tended to concentrate on the needs of the patients and their focus would be directed on their patients.
- Discomfort during the interview: Some of the participants seemed uncomfortable to continue with the interview. Some even mentioned that it was as if they were divulging the information they were not supposed to say for family's sake. Some

showed their discomfort by constantly checking the time and the expression of having to go and help the patient.

- Inability to understand the question: Some would not understand the question asked until the researcher would ask it the other way or paraphrase it to the participants' understanding without altering the meaning of the question.
- Duration of the interviews: the researcher could not be objective about the time spent on individual interviews because some participants became uncomfortable when they felt probing was too personal, whilst others continued talking such that the researcher had to intervene and redirect them to the question.

The interviews were terminated when the participants kept on repeating information or discussing similar issues even at different venues. According to Streubert, Speziale and Carpenter (2011:68), data saturation has occurred when no new information has emerged from the participants and the data being presented is a repetition.

4.4 DATA ANALYSIS AND INTERPRETATION PROCESS

In order to provide congruence between the study theoretical underpinning and the research methodological process through which findings are analyzed and interpreted, the researcher viewed caregivers as a whole person with body, mind and spirit in the interaction. In her interaction she was firstly of the cognizance that participants are actively engaged in the text thus co-constructing the reality as they broke the experiences into small parts that finally emerged into patterns and themes (Gan, Campbell, Gemiinhardt & McFadden 2006:588).

Secondly, while trying to find clues about the meaning in the participants' phrases of their experiences, the researcher acknowledged that all roles and experiences within the family are not only not connected, but are co-constructed by the family members as a system (Becvar & Becvar 2009:12). Thus, when planning the data analysis of transcripts, as well as field notes, the researcher was also searching for signs and actions that indicated the way in which the participants were trying to make sense of their reality (examples in their utterances).

According to Creswell (2009:184), preparing data for analysis, coding, categorizing and identifying themes in the qualitative data are the primary concerns of data analysis. Creswell (2009:345) also indicates that data analysis in qualitative studies starts with organizing data into manageable sizes. With qualitative analysis, the focus is on unpacking both explicit and hidden meanings through iteratively examining the data.

Engaging in analysis involves researchers dwelling with their data, examining it and then progressively deepening their understanding as meanings come to light (Finlay & Evans 2009:145). De Vos (2005:334); and Henning et al (2004:129) stated that in an exploratory and descriptive qualitative research data analysis is an ongoing, emerging and non-linear process of taking apart words, sentences and paragraphs assigning categories to make meaningful comparisons upon which interpretations of data is based. Brink et al (2006:55) further mentioned that qualitative analysis is a process that integrates non - numerative data and reducing them into themes through exploratory, descriptive qualitative coding procedures.

The data on the experiences of family caregivers of patients suffering from TBI was expressed by the participants themselves as they lived the experiences and were analyzed using Tesch's steps of analyzing qualitative data as detailed in Chapter 3. As already mentioned in the previous chapter, in this study some of the audio recorded interviews were transcribed from Xhosa to English.

Data saturation was reached when no new themes emerged from data collected. The themes and categories were discussed with the study supervisors and consensus was reached. From the semi- structured interviews conducted with the participants of this study, it emerged that despite differences in the duration of being a family caregiver, there were several themes that appeared to be common across the experiences of participants.

The key themes that were identified through the process of thematic analysis can be found in Table 4.2. In this study three main themes, five categories and fifteen subcategories emerged following data analysis.

Table 4.2 Themes, categories and subcategories that emerged in the data analysis

Theme	Category	Subcategory
1 Experiences of caring for a TBI relative	1.1 Grieving and trauma	1.1.1 Hearing the news 1.1.2 Experiences in hospital
	1.2 Feelings of despair/denial of the condition	1.2.1 Loss in the psychological, speech, cognitive, emotional and physical aspect of the individual 1.2.2 Financial constraints 1.2.3 Loss of companionship and status
	1.3 Lack of information from healthcare professionals during the time of hospitalization	1.3.1 Caring for the relative 1.3.2 The disease process and non-acceptance by community 1.3.3 Non-availability of rehabilitation services/centres caring for TBI patients
	1.4 Effects on the family	1.4.1 Forced changes in family roles 1.4.2 Lack of support to care for family member (family and social) 1.4.3 Lack of independence
2 Challenges with long-term caring	2.1 Fear and uncertainty	2.1.1 Uncertainty about the future 2.1.2 Fear to leave patient alone
3 The needs of caregivers of TBI relative	3.1 Coping mechanisms	3.1.1 Need for rehabilitation services and information for caring for patients with TBI 3.1.2 Psychological care services - counselling 3.1.3 Improvement of infrastructure

4.5 DISCUSSION OF THEMES, CATEGORIES AND SUB-CATEGORIES DERIVED FROM THE DATA COLLECTED

4.5.1 Theme 1: Experiences of caring for a TBI relative

The sudden nature of hearing the news of a family member who was in a serious accident as well as the day of the accident left most of the participants traumatized and shocked. The following quote emphasizes how traumatic this experience was for the participants:

> "I shall never forget that day of the accident … it was like … very traumatic … yes that to me was the most traumatic experience of my whole life. I've never been in a situation like that." (AD)

After hearing the news of their family member's injury, most of the participants were left with a sense of shock.

4.5.1.1 Category 1.1: *Grieving and trauma*

The accident that caused their family member to sustain a TBI was a traumatic experience for the participants. They reported that hearing the news about the accident was very traumatic and this was compounded by their experience in the hospital which was particularly traumatic,

> "she was unrecognizable, oedematous and shaved on the side of the head, was really bad. I felt numb, it was as if I am in a bad dream." (AG)

Some grieved an ambiguous loss which meant that even though the patient is physically present, emotionally and psychologically he is absent. The families were uncertain about how to grieve losses that were ambiguous. This is a disenfranchised grief, not a grief publicly recognized by society. The families were uncertain about their loss because the loss was unsanctioned and unrecognized by their community.

> "You cannot really sit and have a real conversation with him either- you have these odd little conversations." (AD)

4.5.1.1.1 Subcategory 1.1.1: Hearing the news

The way the participants received the news of their family member's accident were through different sources some were through family members, friends or healthcare professionals that contacted them telephonically. This news involved very vague descriptions of what happened to their family member and how serious their injuries were. One participant said she received a phone call from her hysterical son about her husband's accident. She was instantly thrown into a state of emotional turmoil and her reaction was of shock and disbelief. They experienced feelings of anguish, some felt panic, anxiety, and disappointment when their plans and dreams for the future involving the survivor and their hopes for their families were ruined.

Without any forewarning, their day to day life was radically altered, some had to close the business they were starting, had to change places of work or work longer shifts in order to make up for lost second income. Uomoto and Uomoto (2011:360) in their study of the impact of TBI on the family and spouse found a similar combination of responses in family members of critically injured patients on first learning about the injury.
Sustaining a life altering injury so suddenly propelled the participants into an unintended and unarticulated territory. They hovered between hope and despair as his condition fluctuated.

> You struggle to wrap your mind around the suddenness of it all. It was as if I'd taken a quantum leap into a parallel dimension. In an instant life as I'd known it, as we'd known it, up to that point, came to a standstill - and was forever changed." (AC)

4.5.1.1.2 Subcategory 1.1.2: Experiences in hospital

Participants reported a number of challenges relating to their experiences in the hospitals when they visited their family members. Challenges included seeing their family member in the hospital after the accident, the type of care received in public hospitals and the challenge of the protocols one has to undergo before seeing one's patient like having to wait for visiting time and inhumane disposition of other healthcare workers.

The condition in which they found their family member in was also traumatizing.

> She was full of tubes and machines which were making sounds … Was very scary." (AE).

One participant stated that she would sit in the hospital chairs the whole day so as not to miss any visit, hoping that she would see some improvement. This was a very painful experience as she would disregard her own health for the sake of her husband. Some participants felt that their relatives were transferred back to the rural hospitals prematurely under the pretext that there were limited beds in the hospital.

4.5.1.2 Category 1.2: Feelings of despair/denial of the condition

The family caregivers who participated in this study reported that they had experienced a sense of despair in having a patient with brain injury in their homes. The older family caregivers had hoped that their young children would care for them in their old age but it was now the reverse of those hopes (AA). This theme was consistent with all family caregivers although it varied in intensity and degrees.

Since the injury of the member of the family, some of their despair was related to the sudden injury of a previously healthy person to somebody who would be dependent on others indefinitely; and some related that desperation to them having to abandon or sacrifice their other commitments as well as their future plans in order to focus on caring for their patients. The sacrifice was never ending as the patient kept presenting with different symptoms.

> Each stage brought its own problems. Just when you think you're over one hurdle, there is a different hurdle, you live it throughout" (AB).

> "Sometimes I have to put off my needs for the needs of my husband, for instance, we have to pay for physiotherapy and counselling now and again so even if I wish to buy myself something like a dress (I am making an example) I have to think how I am going to patch up for that waste. I now become guilty when I need to do something like that when I know I won't be able to pay for the medication of my husband." (AC)

All of the participants reported that the consequences that followed the TBI were a challenging experience. Specific challenging consequences reported by participants included personality changes, lack of independence, memory problems and speech problems. Other less common but challenging consequences perceived by participants included epileptic convulsions, controlling behaviour as well as attention seeking.

> “My home has turned to be a prison; it is so cold. It used to be filled with laughter and love but these days we all fringe when he is around because he does not see anything good in all of us. We fight a lot and this emotionally hurts me when he says things that he does not remember the following day. We go to bed angry – something we never ever did before.” (AC)

> “He is very egocentric and sometimes childlike - does not appreciate others as having distinct needs and feelings of their own - he is just attention seeking. Sometimes he does things like messing the bed just for me to attend to him and I find myself asking God what I have done to get such punishment.” (AE)

4.5.1.2.1 Subcategory 1.2.1: Loss in the psychological, speech, cognitive, emotional and physical aspect of the individual

This loss experienced was related to the loss of the healthy, uninjured relative be it a mother, father or child, the loss of the caregivers’ own plans for the future as well as the losses experienced as a family. It was the loss of the quality and nature of the relationship that they had with their relative until TBI occurred. Because one is unable to do the roles he used to do, the family caregiver has to take over in an effort to assist the neurologically impaired. The caregiver’s plans for the future are the disrupted immediately there are shuffling and re allocation of roles.

Their loss was also related to the changes in the individuals physical, psychological and personality changes. Loss of independence and increased dependency on the caregiver was mentioned by many participants. As mentioned in Chapter 2 studies have shown that individuals who present with executive functioning difficulties like problem solving, self-control and initiation of activities may have significant difficulties in regaining independence following TBI.

“I just have to stop doing whatever I was doing immediately she wakes up to redirect her to do an everyday function. This is really frustrating, but what can I do?” (AE)

- *Psychological loss*

The participants in this study described communication, cognitive and behavioural changes in their adult patients since the neurological event. Particularly concerning to the parents were the behavioural and personality changes that were evident in their injured child. These behavioural issues included episodes of swearing, shouting, poor behavioural monitoring and a child-like response to confrontations.

All the participants in this study reported that these behavioural disturbances resulted in their experiencing sadness and frustration, once again emphasizing the difference between the individual before the incident and the one after. They described their feelings regarding the psychological changes that the patients were displaying. According to participant, AC TBI has a capability of changing one's emotional functioning which affects personality traits of both the patient and even the caregiver gets affected.

Some of the patients who previously had patient and well-adjusted personalities before the injury were now aggressive, abusive and irritable. This was a significant challenge and difficult to adjust to for the participants. Most of the participants related how their next of kin had changed emotionally from being a loving, caring and respectful person before the accident to somebody who was always aggressive and shouting.
The changes in personality are demonstrated by the following quotes:

> "I do not know this man anymore that is not my man standing there! Mine is the one who hugs me and make me tea, not that one shouting there. It is not easy; he has changed psychologically; he is not himself at all." (AC)

- *Speech problems*

All the participants interviewed expressed difficulties in communicating with the patients due to their aphasic stages of TBI and changed cognitive behaviour of the patient since their neurological events. Some stated that one had to be tolerant when talking to the patient as he took time to assimilate what was being said to him. When they were with other people the patient would rather sit in a corner away from people.

Six of participants reported that their family members could members not speak and communicate with them immediately after the accident. Participants as family had to therefore educate the patient to speak all over again starting by letting him write what he wanted to say on a paper. This would take a lot of perseverance and self-control on the part of the caregiver as the patient would be difficult sometimes and would not want to cooperate. Participants also highlighted their frustrations when their patients displayed cognitive communicative difficulties, like, they would take long to process information when one was trying to have conversation with the patient. There would be lack of spontaneity in the interaction which would trigger their emotions.

> “He stammers and you cannot hear what he wants to say and when he sees that you are not attentive becomes very aggressive. I just feel pity for him, you know, he is a gentleman, it’s just that he is not well now.” (AG)

All participants perceived changed cognitive behaviour as one of the major consequences of sustaining a TBI and all of them perceived this as challenging. Some memory problems that were perceived by caregivers included problems with remembering faces, going blank when there was a need to solve a problem. All participants were aware that their patients had problems with remembering things from before the accident and had vague picture of what happened in order for them to be admitted. The following extract illustrate the problem:

> “When we meet somebody who happened to have known about the episode she will smile and talk but when we move away from that person she will ask was it so bad.” (AE)
>
> He takes time to responds to commands. Sometimes gets irritated just out of the blue, which is another thing that made me to decide to leave my work so as to be there to protect my wife and family.” (AC)

- *Emotional loss*

Most participants reported that they experienced several emotional challenges that made coping with the caregiving role difficult. Some of the participants spoke of how emotional behavioural change had occurred to their patients who displayed unwelcome behaviours, unprovoked. Specific personality changes that were experienced as challenging by the participants included child-like behaviour, demanding behaviour and anger outbursts, unpredictable and inappropriate behaviour.

One participant who was giving care to a young male patient stated that he was no longer interested in creating relationships with his peers such that she doubted that the relationship he once had with a girl was still sustained. This patient was suffering from dis-inhibition which is a consequence of a damage to the frontal lobe structures which results in blunting of various social skills and a tendency towards inappropriate behaviours (Chung, Pollock, Campbell, Durward & Hagen 2013:1243; Lippert-Gruner, Kuchta, Helmich & Klug 2006:569-574). When they were with other people the patient would rather sit in a corner away from people.

> “My mother, you know nowadays she is like living in another world. It is like I am babysitting a grown up woman because she also has these temper tantrums.” (AD)

Below is the remark from the participant who explained her hurting experiences of having to endure aggressive behaviour of her son and frustration that she could not give him to anyone because she feels she has a duty to care for her son regardless of the challenges that she meets.

> I have thought about this many a times and I've kind of put it out of my head but it comes up especially when I am stressed. But if he would have died, and I'm glad that he didn’t and has like, pushed through, I'm really happy, but if he would have died everything would have changed, we would miss him terribly; we would have mourned him long enough but would try and bring our lives together and our life would have changed a lot by now - it’s the 3rd year now, we'd be on the road to healing or back to our new normal life but like now after 2 years I am still mourning the loss of a living son as I have to deal with all the anger and uncharacteristic behaviours that he puts off. I am the one suffering the most because I am with him twenty-four seven, he even mishandles me sometimes and I have to hide the bruises from his siblings.” (AF)

She stated the reason for hiding the scars of the untoward behaviour from his siblings as because they had warned him prior the accident to change his ways of living but he would not, hence after the accident they wanted him to be sent to an institution in Port Elizabeth.

Several participants reported that the anger outbursts, which are a common consequence of sustaining a TBI, as extremely challenging. This involved getting angry quickly, working themselves up into a panic state and experiencing significant anger and aggression to the point of damaging property. In order to counteract these outbursts participants decided to engage in roles that were originally done by the patient.

> “I have taken over on things that he used to do because nowadays he does not have any tolerance, so if he can’t fix a tap he breaks it. I have to be with him to assist all the time.” (AF)

The participants did not know moment to moment how the survivor would react to any given situation. During periods of peace and calm the families found themselves anxiously wondering when the next outburst would come, knowing that it might be totally unexpected. It was difficult to re-establish a rhythm of living because there was no consistency in their volatile home environments. In addition, the participants reported that they had been made acutely aware of the fragility of life and how quickly life circumstances could change.

Participant (AE) stated that it was difficult for her to tolerate the unpredictable outbursts, as they would be displayed when sometimes they were on the road or in the restaurant. She always finds herself having to explain to people that the person she is with has a problem.

> “We always walk on eggshells because we do not want to irritate him.” (AE)
>
> “I have to always caution the kids not to make noise, not to bombard his brain.” (AC).

- *Physical loss*

One participant explained her shock and disappointment in seeing her daughter in bandages immediately after the operation of the brain.

Another participant described the increase in her responsibility as she had to ensure that the patient is safe because of his physical disability. This meant that they had to adjust some living conditions as they had to share their bedroom with the patient to make it easy for them to supervise her at night. This shows that there is no end in mothering your child.
A mother will do it until the end of her life this is the responsibility of being a parent. When the daughter of one of the participants was being discharged the family caregiver recognized that physically there was something wrong with her as she had a limp, she mentions that:

> “When our children grew away from us we thought, at last we were going to have time to ourselves then this happened. I do not go anywhere even mothers’ union because I have my daughter to care for.” (AE)

Physical changes gave rise to awareness of safety concerns for caregivers. One participant related how, due to the nature of the injury of the relative, physical defects and fear to self-harm makes him to be supervised in all activities. Family caregivers have to change their future plans to accommodate their patients.

> “When he is using a bath we ask him not to close the door even when he says he can cope, because we are anxious that he may fall there or something may happen whilst there like having a fit.” (AB)

> “I am frightened now about the extent of brain damage he is having, people usually say visible scars show what is inside, it is like that even here you don’t know what/how he thinks; he takes time to respond to commands.” (AE)

The above statement is from the parents of a patient who has scars and deformity as a result of the accident he was involved in. This frustration was also highlighted by one participant who had her daughter molested by her boyfriend who stated that her daughter has been very beautiful and now she was having scars and unable to care for herself.

4.5.1.2.2 Subcategory 1.2.2: Financial constraints

As mentioned in Chapter 3, the context of the research study is in an area that is characterized by dire poverty and dilapidated homes, in the worst rural areas where the researcher had sometimes to abandon her car and walk by foot in order to reach the homes of the participants. Family caregivers were challenged to meet the basic needs for the whole family. This problem was compounded by the fact that TBI patients had special needs to acquire in order to maintain the health status that would enable them to be asymptomatic. These special needs included trips to the hospitals and health professionals; medication and safety measures.

It transpired that some participants were using their old age grants, child grant and pension funds to supplement what the family were living on in order to keep the family above the water. Some caregivers had to make ends meet or be assisted by their neighbours. Some participants explained that they had applied for disability grants but they expressed their disappointment to the slow processing of grants applications and to the absence of social workers in their communities.

At times they had to resubmit the application forms as they would be told that they had been misplaced meaning that they would have to wait for longer periods again. Literature cited in a study by Tshililo and Davhana-Maselesele (2009:141) supported the findings of this study in that the family caregivers were frustrated because social workers delayed processing their applications for social grants.

The grandmother who was caring for a young man who was hit in the head through assault was the worst poor participant. She explained that she depends on the community members most of the time as she used her social grant money to assist them in other patients' needs like medication and transportation. She expressed her gratitude to her community as she said that they were taking care of her and her grandson by bringing her food and some would not charge her for transporting them to hospital.

> "Now that it is time for harvest I shall be brought ukwindla (fresh organic vegetables) by everybody in the community." (AA)

Participants explained that they were experiencing changes and constraints financially and were unable to plan for their future in the circumstances. There were worst financial problems in families where the survivor of TBI was the breadwinner. "We had planned to move to a better house in a bigger town but now our monthly income is reduced; I really feel the pinch! Money is being spent on adjustments in the house and medications." (AG)

Planning and predictability of the future are highly valued in society as predictability provides stability and security in life. Most participants expressed feelings of having their dreams shattered by TBI. Their frame of reference was that life was unpredictable and unfair. This made them to be anxious, sad and angry about what life has brought them. In a moment their lives were perfect living their dreams but all those were forever changed and they were no longer able to rely on their previous understanding of the world. One participant said:

> "I had to change the type of work I was doing so that I could earn more in order to patch up the gap caused by the loss of another person's salary." (AC)

> “I cannot quit my job as I am the sole breadwinner. I have to rush home during my teatime to give him something to eat and to administer his medication. In some other days I seek assistance of someone at my home to come and assist with his caregiving needs whilst I am away.” (AG)

Participants had different needs for spending money. Some needed it for transport purposes as they had to occasionally hire vehicles to transport the patients to healthcare centres in cases where the patients had attacks during the night and even taking the patient for reviews as they had difficulty walking and crossing the streets. Some needed extra funds that would cater for paying for extra assistance they needed, make changes in their homes in order to accommodate the patients and some needed funds for food as they did not have enough because they depended on the old age grant for everything.

The participant whose son had received insurance money said it was being spent on medical expenses and attorneys as the patient was the driver of the vehicle that was involved in the accident and caused death of some of his friends. Some participants were assisted by siblings of the patient who would always ensure that the families are comfortable and even take turns in relieving the family caregivers by taking the patient to their homes or to their pastime sports.

Most participants requested that there should be social grant or caregivers’ allowance for family caregivers and for TBI injured which would assist them in buying food, clothing and pay for their medical expenses.

> “Financially it is very difficult for us now because we have only one income. We don’t have any financial assistance; and because of financial difficulties I can’t always be there out with my friends even when there is somebody to stay with her, you know moss, and young people go out to eat. We have to pay for physiotherapy and counselling sessions from our own pockets. There is no financial assistance or grant from the government.” (AD)

> “As far as finances are concerned we make ends meet with the little we have”. (AH)

4.5.1.2.3 Subcategory 1.2.3: Loss of companionship and status

One participant commented on the loss of companionship with her husband when her daughter was in hospital they had to take her children to stay with them and she also had to move back to stay with them post discharge from hospital. She said they lost time to spend together with her husband because she would be busy preparing for her grandchildren and their mother and they could not go anywhere alone as they could not trust anyone with their daughter. They found themselves busy because the husband had to assist with home works.

> “Some other families have even bigger families because of grandchildren. We cope with the little we have in spite of the increased cost of living. Our family has increased now but we are not complaining.”(AF)

When asked about their relationship as a couple, one participant explained that it was difficult to regard her husband who suffered TBI as a partner as he was no longer playing the husband roles any more. He was staying with her husband for the sake of the stability of their home and their children.

> “It’s like a joke right now; it’s a lot like … roommates. I still love him and the kids adore him, but there is nothing beyond that. He leaves me watching television and by the time I get to bed he is fast asleep.” (AC)

She also mentioned that her husband had changed from who he was. Before injury he was a people’s person, somebody who was good in initiating social interaction with ease. The participants highlighted the fact that after discharge an inverse of what initially happened occurred, he is no longer a people’s person and is always visible at home.

It is this stark visibility of a problem that sometimes seems to distress the family caregivers as they know how many friends he once had.

> “He was a very busy person before injury, being a local club coach … even in hospital when he was admitted my husband used to have a lot of visitors such that they had to be restricted to two per visit in order for him to get rest.” (AH)

One participant related that when they took a holiday to the seaside resort she expected that they would enjoy themselves but immediately they booked in their room her husband got into bed saying he was tired. She did not enjoy their holiday as she had anticipated because she was alone inside as her husband was no longer with her mentally.

4.5.1.3 Category 1.3: Lack of information from healthcare professionals during the time of hospitalization

The participants talked about the challenges of being in a situation where you did not how they could manage TBI in their families. There was an appreciation and longing for people in their families and communities to know more about brain injury. They reported that they did not know what to expect during recovery stage of their relative. AA reported that she did not know how to handle her relative when he started to have fits.

> "I actually do not know quite how to handle it." (AA)
>
> "His parents think I am keeping him to myself, they say I must be happy he is back … He is not back at all …" (AH)

It is the lack of having people around that understand what is going on that makes it a lot worse. All participants reported lack of information from healthcare professionals. Because of some of the participants' background and their ages few knew that they could get information through information technology and did not have to base their hopes on other caregivers only.

4.5.1.3.1 Subcategory 1.3.1: Caring for the relative

Most participants reported that they were not given sufficient information by the healthcare workers regarding caring for the person with TBI at home nor were they referred to any professional or service at the hospital before the patient was discharged. They only got some information from other caregivers about the therapies that help their relatives with TBI. Many caregivers felt as though the medical staff were speaking beyond their understanding. The lack of information about the condition made them to feel unprepared for caregiving needs of their relatives.

Some complained that the information given by healthcare professionals was too complex to be understood. They were not adequately informed by medical professionals about TBI and its potential consequences. When they did receive feedback it was often too complex to be understood, therefore, families lacked a frame of reference to be able to contextualize any knowledge received.

Families related that in their traumatized state, they were unable to absorb spoken information and convey it to other family members.

Providing information before discharge is complex because families may not know what questions to ask, what information they will need or what problems they will face after discharge. Studies have shown that families always complain that providers did not prepare them for the transition home because they typically do not recall information provided to them during discharge, partly because it is not relevant at the time.

According to Aitken, Mele and Barret (2004:567), because caregiver distress and worsening family functioning are often associated with behavioural and affective symptoms of TBI, information should be provided regularly for several years post injury.

> "I wish I would have asked more questions, especially about the hospital workers roles so I would have known who to ask what questions." (AI)
>
> "You ask yourself when does this end; what did you do to get this kind of punishment (crying)". (AC)
>
> "When I asked the doctor about the prognosis of my child he said we should wait and see - take things slowly, as he put it." (AD). I was informed that he had sustained a moderate brain injury which would take time to heal. They did not get deep to what is going to occur but they said he may have episodes of headaches until he is recovered." (AB)

Responding to lack of information about patients, O'Callaghan et al (2011:224) and Le Febvre (2005:590) explained that health providers report that although it is important to provide family members with information they are justified in the vague nature of that provision given 'uncertainty' about the clinical evolutions of the casualty as well as worries about upsetting the family unnecessarily and conversely not giving false hopes about recovery. Because of lack of information given to the relatives whilst the patient was still in hospital, participants were not aware of the long-term status of the condition.

The abovementioned experiences on caregivers' lack of knowledge about the relative 4.5's condition concurred with the findings from a study on caregiving for Thai children with HIV infection by Thampanichawat (2008:203-204) and a study by Wacharasin and Homchampa (2008:392) on a Thai family caregiving model.
These studies also confirmed that primary caregivers needed to know the truth about the diagnosis of their relatives in order to decrease the stress and anxiety caused by not knowing what was wrong with their relative.

4.5.1.3.2 Subcategory 1.3.2: The disease process and non-acceptance by community

The majority of participants expressed difficulty in dealing with the clinical aspects of health of their patients like they would not know how to quieten one when he is aggressive or how to stimulate his brain when not acting as expected.

Perceived problems with remembering things from before the accident as well as during the TBI survivor's hospital stay were reported by caregivers as illustrated by the following extract:

> "After the accident he's lost a section of memory from before the accident and he's lost quite a big section after the accident, he looks for something that is in his hand." (AA).

These problems make the caregivers to be unable to provide quality care for their loved ones. One participant on her reaction to non-acceptance by the community said:

> "When you walk with a staggering person in the shopping mall people stop what they have been doing and watch you as you pass and you can feel their eyes, you know! (AD)

> "I just leave him and go to my room and cry and thereafter compose myself because I can see he cannot help himself, he is not well, he is sick." (AD)

Because of lack of knowledge about TBI, some of the participants believed that the accident that led to TBI was due to witchcraft. Reasons stated were, among others, jealous neighbours and friends, colleagues who did not want the patient to prosper and achieve professionally and career-wise.

> "How does my child end up like this when he was progressing so well in his work? (AB)

> "My mother was due for a promotion then this happened, you don't know what you don't know." (AE)

The participants who believed in witchcraft explained that they were visiting alternative healers like prophets and traditional healers for help and they explained that they did not see that move as useless because as Blacks they believed in the ancestors so there may be possibility that their ancestors were trying to communicate with them.

> "We, Black people believe in tradition and culture. What would make my child to be like this when he was comfortable at work and progressing well? I know he has been bewitched at his work because of his position of authority." (AB)

Two of the participants perceived TBI to be God's will and were awaiting his intervention in their daily life and the condition of their loved ones. They further explained that the incidence of TBI had caused their faith in God to be strengthened. One participant expressed her concern on the lack of knowledge in the society generally regarding TBI. She complained that society treats persons with disabilities as not normal and it does not welcome differences. This narrow way of thinking about TBI survivors as abnormal resulted in caregivers feeling distressed and isolated.

> "You would see people when I take her to the mall; they all stop what they have been doing to look at us." (AE)

Expressions by some participants who had beliefs that the accidents may have been caused by powers of darkness since their patients were doing well in their workplaces were related to lack of knowledge about the pathophysiology of what happens to the brain when one has a TBI accident. What was painful was that they were spending their money on prophets and traditional healers seeking health for their patients.

The data fully indicated that participants were not adequately informed by medical professionals about TBI and its potential consequences. When they did receive feedback it was often too complex to be understood, therefore, families lacked a frame of reference to be able to contextualize any knowledge received.

Families related that in their traumatized state, they were unable to absorb spoken information and convey it to other family members.

When asked about their plans for the future one participant stated that she had not brought herself into thinking about the future as she believed that this was just a passing phase in their lives. Greenwood, MacKenzie, Wilson and Cloud (2009:1122) suggested that avoidance of thinking about the future was an indication of having accepted the situation as well as reducing the risk of disappointment. They further suggest that these feelings should be acknowledged by the healthcare team when formulating support programs for both family caregivers and their patients.

4.5.1.3.3 Subcategory 1.3.3: Non-availability of rehabilitation services/centres caring for TBI patients

All the participants cited the fact that there were no rehabilitative services available for their patients. One participants complained that if her mother was identified immediately that she had suffered brain injury she could have not suffered that much, therefore, she was criticizing the inadequacy of health services in the Eastern Cape. Her mother was diagnosed by a private facility after suffering a fit otherwise, she was treated and discharged on the day of injury.

Most of the participants said their patients did get rehabilitation services when they were still in hospital but these services came to an end when they were discharged. Those who were still getting physiotherapy services were paying for such services as in private facilities.

Participants did mention, however, that professional nurses were visiting them though they would come without medications so they were not of any great help so to speak.

Regarding the distance from the healthcare facilities, participants explained that ambulances could not travel on bad roads; they had to use wheelbarrows as transport or had to carry the patient on ones back. This was very pathetic considering that the participant who mentioned that is an old lady against a young person but they have no other alternative as the roads are in a poor state.

Some participants expressed that their felt that their own mental health is adversely affected as a result of the stress of having to look after the TBI survivor which they do not know whether it would ever heal or not; depression, fatigue and utter frustration came through during the interviews.

> "We are far from everything here, nothing comes to us, nothing is happening, we hear about things happening in other places, not here. Our counsellor had promised us that there will be a mobile clinic and social work people coming to us; that was a long time ago. We are just forgotten here. Sometimes it depresses me to death to think, wow, I cannot help him. I do not have money. I cannot tell him that I do not have money, where do I expect him to get it if I do not have it." (AC)

4.5.1.4 Category 1.4: Effects on the family

The studies on traumatic brain injury has alluded to the fact that a neurological event does not only affect the individual only but the caregiver and the family system at large (Yeates et al 2006:78). The relationships between the members of the family do not start when there is a crisis, therefore, if they have something against the caregiver they will not be of assistance.

Literature states that family members suffer from distress which becomes evident in family systems functioning. Some difficult family members would not want to assist because patient is living in the rural areas.

> "I leave my husband with his siblings sometimes and they usually take him to his sport, His sister is paying for his rehabilitation expenses. She will not give up on him and this also gives me strength to soldier on." (AI)

Participant AI was assisted by her husband's siblings because they would come and take him to the sport field so that she could get time to rewind. Research study by Hutton and Caron (2006) which investigated reactions of siblings to patient with autism found out that the siblings experienced distress when they could not communicate with the autistic sibling.

Most of the family caregivers in this study were getting assistance from the neighbours and family structures. They took on roles they never imagined, as they navigated the medical system, insurance systems, financial responsibilities, and becoming caregivers.

Most of the participants described how they were overwhelmed about their roles of being the caregivers of the TBI patients or taking charge of the household and having added responsibilities but were confident that they were coping though there were times they wished to give up but they knew they would be seen as failures in their culture. Some of the participants spoke about how their role of being a wife, daughter or grandmother had now changed to role of a family caregiver.

4.5.1.4.1 Subcategory 1.4.1: Forced changes in family roles

The experience of TBI to the participants was mainly that of taking new roles and change in identity within the family. One participant who was a wife of a patient said that she wanted to conserve what the family used to represent but was faced with the reality of the current situation which was daunting. She was also challenged by having to adjust her character and emotions where she had to learn to control herself, keeping her temper down.

Participants who were nursing their partners expressed the strain of having to do chores that used to be done by their husbands like fixing broken taps as the patients do not have tolerance nor strength to do them.
Participant AC also said she had taken over paying bills and doing shopping something that used to be done by her husband. One participant said she had to learn to do things herself including the knowledge of business when the role of being a financial provider was transferred to her after her husband's injury.

This is a growing trend in developing countries like South Africa, that females are now becoming heads of most households. According to the statistics of the Department of Health Medical Research Council ORC Macro (2007), nearly half of all households in South Africa are headed by women. Role changes within the family are common and frequently necessary after the neurological event this being due largely to the effect that physical, cognitive and communication difficulties have on the injured person's ability to adequately fulfil his or her role in the family.

The participant who was the only grandparent interviewed in this study described the effects that the adult child's neurological event had on the family as a whole, and not just on her as the family caregiver. Schatz, Madhavan and Williams (2011:598) explained that intergenerational families are common in the current South African context and may occur not only as a result of illness or disability within the family but because young parents abandon their children and go to bigger towns.

Some participants commented that an intergenerational family structure has always been present in their cultures even before the neurological event hence when the injury occurred their older parent caregivers had to take over caring for the child and grandchildren.

> "It becomes like your job." (AA)

4.5.1.4.2 Subcategory 1.4.2: Lack of support to care for the family member (family and social)

Analysis of the transcripts showed that the majority of the participants highlighted the importance of receiving support from the family, friends and even the healthcare professionals which was lacking in their circumstances though necessary. Participants stated that the practical implications of the substantial physical emotional financial and time demands created by TBI caregiving meant that those who assumed primary responsibility for it could not cope with everything on their own without the support of the family. Most family members helped with tasks of caregiving like feeding and fetching medications but financial assistance was scarce.

Financial assistance was the most needed commodity as it would assist to cover a range of additional expenses associated with the caring. Some participants stated that old age grant eased the burden for cases like transportation. The siblings of patients kept their parents and their relative company and would even take the patient for holidays in their homes as a way of relieving the caregivers.

Participants reported that though they regarded emotional support as the most important in their need they also needed practical support from people.ost participants in this study highlighted that while seeking family assistance was very important in helping them cope with the situation, the success of this strategy depend on the pre- existing relations and is not necessarily guaranteed. Some of the participants explained that they were receiving practical support, some from people they never regarded as friends before the injury but who were of high value to them now.

One participant mentioned that she would be relieved if she could have somebody to assist the patient in tasks like bathing. She stated their mutual discomfort with the confusion of caregiver and parenting roles when they had to bathe and feed the patient, as evidenced by the statement from the mother.

> “In our culture you respect an individual of another sex even if it is your child; therefore, seeing him naked is very weird for me. Moms don’t see their old sons’ private parts, they just don’t.” (AB)

The father mentioned that he decided to stop working because he discovered that he would lose his wife because she would not have time to relax because the patient needed a lot of attention. He said he did not want to be labelled as an absentee father something which suggests that he resists to be a stereotype Black men who say caring is for women.

A major source of happiness of parents is to see their children developing in life having a decent life and raising happy families of their own. But when one child develops a devastating illness and them as parents witness the progressive decline in one’s physical and cognitive decline, it is emotionally draining for a parent. Parents who are primary caregivers to their adult children stated that the role of being a family caregiver was emotionally draining but they were reluctant to always inform people or seek support from their immediate social networks because they did not want to experience the negative cues and reactions towards their children.

Elderly participants mentioned a lack of energy to carry out tasks as demanded by the sick individual stating that they had no energy for carrying out all the tasks related to caregiving owing to their own state of health, which was deteriorating with age. They could not go up and down in healthcare facilities accompanying the TBI patient and to meet all the other needs of such patients.

One participant mentioned that she employed an assistant to help with the caregiving of her husband but he would insult her such that she decided to release her.

A young participant who was a mother to a young child and had to care for her husband said her belief systems were challenged when she had to confront her fears and also to acknowledge her helplessness in influencing the situation. Her husband would always want to sleep saying he is tired or would completely forget important assignments, so she had to see to it that all his tasks are done even if it meant that they are done by her. She voiced her hope for recovery and at the same time was willing to accept what God gave them. The participant's use of religion to deal with hardship was based on culture expectations making meaning of the situation or the tool to use when all else has failed.

According Humphrey, Hughes and Holmes (2008:89) prayer is a vital aspect of religious and spiritual fulfilment to Africans and is a significant component of Black culture. Prayer was the most frequently used method of religious coping reported by the participants in this study. According to *Merriam Webster's Dictionary* (2008), a prayer is defined as an act of communicating with God through words of thoughts. One of the forms of prayer is a collective prayer where a group of individuals come together to pray about a situation.

One participant who was still attending university said she could cope well if her mother's siblings could come and stay with her to relieve her whilst she is writing examinations. She expressed her desperation on her mother's condition because it was causing her to abandon her own essentials.

> "What I loved about my mother's colleagues they would come and assist in cleaning the house and never leave without praying with her." (AD)

One participant shared her experiences about how she felt she had a responsibility to protect their children or shield them from the emotional and behavioural problems of the father suffering of TBI, while also attempting to be supportive of the patient and encourage their children to be understanding even when it is challenging to them.

Those that were nursing their husbands voiced out their ethical demands that they had to take care of their husbands and honour their marital vows with the TBI patients as well as provide as much stability as they could for their children in their households.

> “This is really frustrating, but what can I do?” (AF)

> “I went from being the wife to a caregiver of someone who had always been very independent and active but now is solely dependent on me.” (AH)

> “I had to change my place of work in order to pay bills including medical bills, household and school fees - children have to go to school, you know.” (AC)

Participants were asked how things had changed for their family and how well they thought hospital staff was able to prepare them for their new jobs as caregivers. All participants expressed disappointment in the healthcare system because they were never prepared for such major changes in their lifestyles and daily roles, including caring for and re-socialising an adult person.

The grandparent had concerns for the grandson’s future as she had to supervise the home that the patient used to look after. For her the role change was not a problem for the moment but she was worried of what would happen if she and other grannies who are caregivers like herself became unable or were gone, like dead, what would happen to their patients because there are no places for caring for patients with chronic conditions like HIV/AIDS and TBI.

> “Sometimes it bothers me; having to do this places much pressure on me but I tell myself that I don’t have anyone else to do these things let me do them; as times goes on you get used to the situation and it just becomes a natural thing to do.” (AG)

4.5.1.4.3 Subcategory 1.4.3: Lack of independence

Participants explained how tedious it was to attend to a TBI patient, having to assist in bathing and ensuring medications are taken, going to healthcare institutions and stay in long queues for reviews and medications. Sometimes one has to always caution people around the patient on not being loud.

> "I used to go to bed very exhausted; I would even forget to bath myself and even to eat, because she wanted to be with me all the time, I would literally stand the whole day attending to her. My husband would ensure that he cares for other children like assisting with their homework and food preparation." (AD)
>
> "According to Black culture family stays together, even in adversity and intergenerational cohabiting is accepted in our South African culture.
>
> "I had to release the woman I had hired because he would call her names and would not want to be assisted by her." (AH)

The participants reported their inability to function independently as a challenge. This happened irrespective of the duration of one's period of injury. Some of the patients could not do the most basic tasks like washing or eating and had to be assisted meaning that there had to be somebody with him all the time.

This lack of independence affected the participants in doing things that they used to do before the injury like if they needed to go somewhere they had to think of the security of the patient. One participant mentioned that she took her husband with her even when going to her home in order to ensure his safety.

4.5.2 Theme 2: Challenges with long-term caring

Most of the participants reported the various social challenges they encountered due to caring for their TBI victims. They cited challenges that included isolation and discrimination.

All the participants agreed that they felt isolated and excluded from all social activities because of their busy schedules. They no longer attended community gatherings, church services, funerals, weddings and traditional ceremonies. The only avenue to socialising available to them was when they were in hospital or health centres where they would go for reviews and be able meet other people in the same predicament to support each other.

4.5.2.1 Category 2.1: Fear and uncertainty

Further to the theme of loss, was the feeling of fear. The subtheme of fear and uncertainty was divided into two, these being fear of the future, fear to leave the patient alone and the caregivers' fears related to caring for the injured adult relative. They stated that it was very difficult for them to leave the relative alone as they feared something terrible might happen whilst the caregiver was away.

The participants had this to say:

> "I have not been to church for about two years now as I have no one to relieve me in my caregiving role even on weekends. I have missed out on meeting other mothers' union members for support and advices. I am now living a solitary life." (AD)

> "I cannot even attend my close relative's funerals as I cannot leave my husband alone." (AH)

Research study by Neursing and Ssengozi (2009:309) concur with these participants in that they also reported that family caregivers experience disruption in their social activities, altered family relations and caregiving often limits the caregiver's time for socialization, attending social events and carrying out income-generating work. In this current study most caregivers cited that they experienced emotional strain due to rejection by other members of the family and community members whereas some were very grateful to those who were supportive to them.

4.5.2.1.1 Subcategory 2.1.1: Uncertainty about the future

The feelings of uncertainty and fear of what the future may hold for the participants is not surprising. As mentioned before, patients with traumatic brain injury depend on other people in all aspects. This means that their future needs to be carefully planned so that in times of misfortune, especially to the caregiver they are prepared for. One participant mentioned that she purposefully preferred not to think of the future but to concentrate on the present. The quote below suggests that for participants AG and AB, attempting to predict what would happen in the future appeared to be a daunting and overwhelming task.

> "I have not brought myself to think about the future. Sometimes it depresses me to death to think---wow! I have to develop coping mechanisms because I have this forever." (AG)

In a research study by Silva-Smith (2007:99) similar findings of avoidance of thinking about or making plans for an uncertain future were identified. This is similar to the sentiment described by participant AG where focussing on the present tense allows for a more pragmatic expenditure of emotional resources and therefore an apparent subjective experienced ability to cope.

Contrary to this perception, a study conducted by Greenwood et al (2009:1122) suggested that the avoidance shown by caregivers in terms of making plans for the future may be seen as an indication of acceptance of the caregivers' situation as well as reducing the risk of disappointment.

Studies conducted by Greenwood et al (2009:1130) and Coombs (2007:113) suggest that these feelings of uncertainty are common in the experiences of persons caring for their loved ones who have suffered neurological condition. They further suggest that these feelings of fear and uncertainty need to be acknowledged by the rehabilitation team when creating programmes to support both the caregivers and the survivors.

The parents who participated in the study expressed concern regarding the plans for the future for their adult relatives, particularly the need for ongoing care when they could no longer be able to provide quality care.

Participant AA was not only perturbed by the condition of her relative but was also worried about his safety as he was involved in a fight with somebody influential in the community. This made her to worry each time he would be missing even during the day. Greenwood et al (2009:1132) suggested plans and strategies that could be utilised to alleviate the stress and tribulations that parents and grandparents would undergo when they were in such situations.

Although the family caregivers had voiced the feelings of hope that the patient may recover fully or more than at present there was an implication and underlying message of uncertainty about the recovery process and the future in general. They reported that they vacillated between hope and despair as the survivor's behaviour fluctuated. They described how vacillation in the survivor's behaviour or poor judgment evoked feelings of instability and uncertainty.

> “You kind of take it a day at a time, when it's going good you think, "Maybe we’ve got it here," and then out of the blue outbursts start. I have a husband and my children’s father with a traumatic brain injury, who is very difficult to live with." (AC)

4.5.2.1.2 Subcategory 2.1.2: Fear to leave patient alone

Most participants expressed a need to have regular health information from the healthcare professionals about TBIs as they had fears of leaving the patients alone, as if something would happen to him whilst alone.

> “It is difficult to attend even women’s union because I fear that he may hurt himself or he may start to have a fit.” (AA)

> “I rather take him with when I go away for a weekend even when going to my home.” (AH)

In essence families experience a catch 22 situation, they are reluctant to leave the patient alone and they get embarrassed when other people visit them. One participant explained that they do not invite people or go to their friends’ home anymore because of the relative’s embarrassing behaviours like shouting and swearing, telling them he does not like them they have overstayed their welcome. They also appreciated the support they got from the community and family members. Prigatano (2005:19) is of the opinion that professionals should aim at addressing the emotional needs of family members during the rehabilitation process as well as thereafter

4.5.3 Theme 3: The needs of caregivers of TBI relative

In the chapter on literature review it was stated that patients suffering from TBI have very challenging consequences which may cause stress to caregivers. According to Guishard-Pine, McCall and Hamilton (2007:36), emotional and social support are considered as helping factors for caregivers to avoid exhaustion and burnout. Support enhances psychological wellbeing, feelings of being in control and a sound self-esteem whereas the absence of support may contribute to factors such as loneliness despair and depression (Larkin 2006:53)

4.5.3.1 Category 3.1: Coping mechanisms

Three out of the nine participants reported that the support they received from their neighbours was amazing and that the neighbours were always there for them, providing emotional, material and financial support when they needed it. Participants made use of various strategies to help them cope with long-term caregiving situations with their relatives.

Some participants experienced many stressful situations and reported that they responded in various ways to coping with the challenging tasks of caregiving. They stated that, in some instances it was possible to assertively change the situation or alternatively adapt in it in order to live with it so as not to feel even more frustrated. Some coping strategies were positive and others were negative but most of the participants opted for positive coping mechanisms thus accepting and viewing caregiving positively. Some participants felt it was difficult for them but they had willingly taken their roles.

> “We go out occasionally so that we mix with other people” “I have learned to deal with it. Anyway he is my husband … in sickness and in health after all he is the father of my children.” (AC)

Most participants generally maintained a positive attitude towards their relative and this made it easy for them to accept patients’ demands and sacrifices that often accompany caregiving. One participant mentioned that she had to get somebody to assist her with household work. Machamer, Temkin, and Dikmen (2004:421) in their study reported that caregivers of individuals with TBI reported higher levels of caregiver burden and lowered coping mechanisms when the survivor had poorer neuropsychological functioning.

> “I am very lucky to have supportive neighbours, they know that I am struggling financially and have been providing care to us in different ways. They had been transporting my kids to school for free.” (AC)

Some of the participants described how they were trying to come to terms as a family with what the new normal life was going to look like. They stated that they were coping well especially with the help of their prayer partners from their churches. Some participants were sceptical about involving their neighbours because they alleged that they did not want to give them something to gossip about. They said neighbours did not understand the plight of family caregivers so when they stopped going to family gatherings or community functions it was an issue.

All participants stated that as the stressors and pressures increased the caregivers isolated themselves and did not let others, even close family members, to know the severity and complexity of their situations. They did not want to ask for help and began operating in a veil of disclosure which consequently had an impact in their health.

> "I hardly sleep thinking about this; my blood pressure has gone up a few times; I have headaches behind my eyes; I know it is stress but I try to block it out for the family's sake." (AF)

This concept of disclosure appears to be culturally prescribed in Black culture. Historically Black women are perceived as strong and resilient hence they are capable of being left alone to maintain the household whilst men go the mines to work for their families. Women are expected to possess the ability to adapt in a society with systemic discriminations and are not expected to show weakness or powerlessness.

Another coping strategy cited by almost all was the hope that the sick relative would get better. This hope helped to keep up some participants' morale during the illness and motivated them to do their best in giving care. This hope is reflected in constant search for treatment to improve their relative's health as reported by one participant:

> "We take him to other therapies where we are told there can be help." (AB)

4.5.3.1.1 Subcategory 3.1.1: Need for rehabilitation services and information for caring for patients with TBI

All the participants said their patients received rehabilitation whilst they were still admitted but after discharge the services did not continue. Those who continued with rehabilitation were assisted by their siblings and some who had financial stability, had to seek healthcare from the private healthcare providers. In this study it was highlighted that family caregivers require information long after the initial injury. The need for relevant updates and follow-ups with medical professionals appear to be important for family caregivers. Some participants reported having occasional visits by the professional nurses only but also highlighted the fact that nurses do not have medications and transport to visit as frequently as the family caregivers would love, though they do refer them for other services.

The majority of participants expressed difficulty in dealing with the clinical aspects of health of their patients like they would not know how to quieten one when he is aggressive or how to stimulate his brain when not acting as expected. This makes them to be unable to provide quality care for their loved ones.

Even after many years of the participants being involved in their caregiving and being in constant contact with many health professionals they continued to show interest in aspects relating to TBI such as the extent of damage and the length of recovery process. Participants felt that it could assist them to be informed of their patients' conditions, kept updated all the time.

> "I would like that all healthcare professionals inform us about the changes in the patient's condition when the person is admitted, not that we have to ask and that the explanations are given in an understandable language not the use of words like Glasgow." (AD)

In the study conducted by Friedman, Sanchez, Griffin, Retmann, Ritman & Partin (2008:206) it was evident that people caring for patients with poly trauma had lack of information regarding how to support their relatives because the field of poly trauma is new and evidence is lacking. Smith, Gignac, Richardson and Cameron (2008:593) noted that significant age related differences existed with regard to the need for appropriate information regarding their loved ones.

The younger generation of family caregivers was more proactive than their older counterparts in that they were able to use social networks and internet to gain information. The older caregivers such as those of this study accompanied by their background of being rural were less likely to seek information on their own. They, however, showed a keen interest in increasing their knowledge of TBI and getting strategies to cope. They were even willing to share the information they have from their experiences with other people even if they have not yet had the experience.

All participants explained their concerns regarding the inaccessibility of health services in the rural areas in as much as their patients could not continue with important rehabilitative services in healthcare facilities near them.

4.5.3.1.2 Subcategory 3.1.2: Psychological care services - counselling

A positive psychological state of mind is associated with searching for and finding positive meaning. In this study commitment to caring was associated with accepting caregiving as part of natural responsibility and viewing the sick relative positively. Most participants stressed that their relative was of good character before the injury. Two participants blamed witchcraft and jealous neighbours/colleagues as the cause of the injury.

Putting on brave front and concealing their hurt, anger and disappointment or anxiety helped the participants to function best. Regarding psychological support participants explained that they would appreciate the counselling services that could be provided to them and they felt concerned because of lack of such services for them in the rural areas yet they voted for the same government.

> "I was never given counselling for being a caregiver for my mother, she was just discharged and that was it." (AE)

Testa, Malec, Moessner and Brown (2006:236) stated that the family plays an extremely important role in survivors' rehabilitation, significantly affecting the survivors' psychological adjustment to injury related disability. The authors further stated that distressed family functioning correlated strongly with increased rates of survivors' neurobehavioral symptoms (Testa et al 2006:236).

4.5.3.1.3 Subcategory 3.1.3: Improvement of infrastructure

Participants felt that the government does not care for them because they hear that there are services that are provided for TBI survivors in other places yet the same services are not available in rural districts and as a result they query the meaning of the concept of equity. "We all voted for this government why are treated separately? There are no nurses visiting us to check on whether we cope or not we are just left in the wilderness no one cares for us." (AB)

All participants stated that the eastern part of the Eastern Cape is forgotten by the government of the day, the roads are in very poor condition. One participant explained that when she stayed in hospital until late she would be apprehensive not knowing if she would reach her home because of potholes in the roads. The government service providers like ambulances and social grant do not go to certain areas because of the condition of the roads making the service recipients to travel long distances before they reach assistance.

> “The government should build us places where we can take our people for socialisation and us caregivers to be able to meet with others. The government should build us clinics of good standards and improve the condition of our roads otherwise we are going to lose our loved ones. These roads become very treacherous when it is wet.” (AE)

> “I will never forget the day when I had to take this boy to hospital in the middle of the night. It was the first day I see him having a fit, I was so shaken! We called the ambulance but when it arrived we had to carry him on our backs to reach the ambulance because my house is inaccessible by transport. I fell three times with him on my back, he is very heavy I cannot carry him but I had no option I wanted him to get treated.” (AA)

These are the remarks of a family caregiver who was frustrated about the conditions of their roads.

4.6 CONCLUSION

The research method employed in this study and the theory used as a lens to observe and interpret data in this study is one way of looking at the world and the research findings thereof are a way of dialoguing about the phenomenon of TBI and how a particular family experiences it at a specific time in dialogue with a specific researcher. It should be noted as well that the families in this study were not forced to participate in the research, they volunteered on their own accord.

The interaction of the families and the researcher and the interaction of the researcher with the data are seen as subjective processes and circular in nature in that all the variables the participants, the researcher and the data collected in this study, are constantly affecting and being affected by each other in the research process.

The following chapter will discuss in detail, the results, strengths and limitations of the findings of the study and their implications for policies and practices that impact on family caregivers of adults with TBI. The chapter will include references to literature on the topics of family caregiver wellbeing, the caregiving experiences and systems of care to determine if these findings are an accurate picture of caregiving and what new information they may contribute.

It will also conclude by offering guidelines of support for all the family caregivers of traumatic brain injured patients in order to assist individuals in realising more success and less uncertainty following the injury of a family member.

CHAPTER 5

DISCUSSION OF FINDINGS AND SUPPORTING LITERATURE

5.1 INTRODUCTION

This study aimed to examine and gain insight into the full spectrum of the experiences of the family caregivers who are responsible for caring for a family member who had sustained a TBI and to understand these through the family perspective. These experiences were investigated by exploring the challenges and the resources family caregivers encountered through their caregiving role.

In this chapter the research findings are discussed and supported by other published research work in the form of literature so as to demonstrate the usefulness and implications of the findings. Upon reflection of the results obtained in this research study it is evident that family caregivers of adult TBI patients experience specific negative reactions both to the incident and the resultant need for care of the patient.

The results of this study have supported the view that family as a system and relationships within the family have a greater impact on the outcomes than the functional capacity of the patient. Some light has been shed on how to better understand the experiences and coping strategies of family caregivers and the support services that could assist them in their caregiving.

Although the family caregivers were faced with redefinition of their roles within the family and the struggle to adjust to their situation, variables such as personality traits, belief systems, family relationships and self-perception played a huge part in the patient's functional capacity. The attitudes of some family caregivers appeared to play an important role in having an outlook for the future which appeared to impact the motivation for recovery.

5.2 DISCUSSION OF THEMES

5.2.1 Grief and feeling of trauma

This study illustrates that the challenges expressed by participants caring for TBI are great and require continuous assessment and intervention of multi-disciplinary approach. The theme of grief, feelings of trauma and indefinite loss resonated through all the nine participants' interviews transcripts. They experienced overwhelming, unfamiliar and frightening feelings of grief and trauma when they were initially informed of the injury. The grief was related to shock of hearing the unexpected news and seeing a normally healthy relative being unconscious and prospect of inability to do things he used to do on his/her own.

The suddenness of the trauma caused the participants' dreams of seeing their relatives prospering in their future to be lost due to brain injury. Even though the posttraumatic symptoms were not clinically evaluated in this study, such signs and symptoms were perceived and reported by the participant caregivers. The sudden loss, cognitively, physically and mentally, of the relative who had been healthy and active could not be obliterated in their minds and as such they felt traumatized by the situation.

The researcher has not seen a research study that has reported on the experiences and challenges the family caregivers go through on hearing about the news of the relative sustaining the brain injury and of them seeing him/her in hospital for the first time. These experiences were documented in order to highlight the challenges that the caregivers face from the onset in order to emphasise the need for them to be supported much earlier in the health/illness continuum.

Participants all reported grief in the significant changes as far as cognitive and mental aspects were concerned and were traumatized with the physical aspect of the patient as they would be intubated and mechanically ventilated. Some mentioned the changes in the physical outlook of the patient, suddenness of the change from a well-adjusted healthy person to somebody who would have mobility difficulties.

Socially, trauma experienced by family members was in losing somebody who once was a breadwinner or head of the family or a respectable person in the community, as a result there was loss of social integration. Social isolation was also referred to because they no longer were able to attend social gatherings as a family and they had to isolate themselves from other people because the society treats an individual with a handicap with disdain. They also felt bad about leaving the patient alone with a helper at home saying that they would be guilty if anything would happen to him in their absence.

Most of the participants explained that they enjoyed when the old characteristics of the patient were displayed and they would forget their predicament for some time. Personality changes such as bursts of anger and unpredictable behaviour were particularly stressing. This is consistent with the previous studies by Gan, Gargaro, Brandys, Gerber and Boschen (2010:5-18) and McAllister (2008:3-10).

This theme led to family caregivers experiencing loneliness as they did not have anyone to talk to. The changes in patients led to increased conflicts and feelings of despair to family caregivers and the family at large. The participants complained of a decrease in the interaction between themselves, the patient and other family members such that they would not invite friends, children and extended family members to their homes in case he would be stimulated to have unwanted behaviour.

> “My husband used to be the initiator of communication - he was the life of a party but now only few of his old friends still remain, he no longer has his social circle, he is with me” AG.

Being able to recognise this seemed to be the way family caregivers coped with the adjustment as the loss of old friendships is very common with patients with TBI.

Two participants stated that their patients were unwelcoming to their previous friends and colleagues post injury. They would sit alone in a corner secluding themselves from the crowd as if they were strangers. The loss of old friends was seen as very hurting but some family caregivers were happy and blessed to have acquired new friends along the journey of caregiving who seemed to be more genuine.

Grieving would also be due to the fact that family structure would be disrupted and this was experienced when one was able to differentiate the period before the injury and after then compare the changes in the patient as far as personality, physical, cognitive and communicative aspects of his behaviour were concerned. This is in keeping with what Myers and Blake (2008:963) say about TBI or any neurological injury, for that matter.

It is therefore imperative that such family caregivers are provided with both indefinite psychological and social support systems in order to enhance their coping skill.

5.2.2 The experiences of role change and family responsibility

All the participants in the study experienced redefinition and reallocation of roles and responsibilities in the family due to the loss of the patient with TBI. The participants related their involvement in tasks that they were not acquainted with as being very challenging because the person who was doing them could no longer afford that. Some of the participants had family members and friends helping them which proved to be very beneficial. Participants could not continue with their future plans because of the reduction of independence in their patients and their inability to participate in activities of daily living.

As the participants were mostly women, they all stated role changes as challenging because they were not confident of being heads of the families, they were afraid of matriarchal society as they were now expected to carry household financial burdens while continuing to maintain their roles as homemakers. Others were voicing their hopes that their husbands would recover and be able to step back into their previous roles. South African society is structured along patriarchal lines of power that requires men to financially support the family while women stayed at home and care for children. Biblical patriarchy also placed men in authority in the family and required women to be submissive. All the participants who were active in church were influenced by these cultural messages and operations of social control.

With regard to the family systems theory employed in this study, it has been demonstrated that the family operated as an open system which would adjust the environmental boundaries in order to accommodate the stressors and maintain environmental homeostasis. Each member and the whole family as a unit reacted to and responded to the environmental inputs into the system and also had interaction with their environment. The inputs into the family system were acted upon and modified by the family. The families went through this process together as a process is defined by how the individual family members describe the process of role redefinition and the personal sacrifices in order to sustain the family as a unit of interaction.

There appears to be an exchange of energies and information between the family and its environment and the behaviour of each member of the family is interpreted or explained in terms of the individual member relationship with the environment and his role in the family system.

The family responded to the input about their new family system environment after TBI and had thus adjusted their roles accordingly. This illustrated how the individual and family dynamics hinder or assist the process of healing. Firm belief in the family helping family was the value that was depicted by the participants in this study.

A lack of acceptable care alternatives and negative experiences with the healthcare system have been cited as a contributing factor to some caregivers' strong belief that the home was the best healing place and the families the best care providers. This was supported by the actions of those caregivers who had maintained a high degree of involvement in providing care even though they were not the primary family caregivers. Their actions reflected their belief that they would always be involved and supportive. One father even said he does not want to be an absent father for his son when he is still living; he wants to be active in the care of his son.

In a study by Joubert (2005:3) it was stated that the ratio of 1:4 of adult males take the responsibility of being family caregivers in South Africa. He stated that although some men did take that responsibility, some of the caring tasks were delegated to female members of the family. Laroi (2003:176) states that family therapists are of the opinion that healthcare professionals involved with families dealing with TBI should first get information on an individual's capacity and role in the family including one's distribution of power and authority before the injury.

The injury necessitates redistribution of roles in the family. In this study some participants took over the roles of their partners, taking over paying of bills and doing household repairs. Parents of another patient took turns with the responsibility of caring for their son. The father was the one with responsibility of fetching medication from the hospital.

5.2.3 Uncertainty about the future

The brain injury raised existential questions for participants. They were engaged in the notion that anything could happen at any given time and that life was fragile. They were wrestling with the existential questions, freedom and choice to move within their lives. They were trying to hold on to a preferred future and hope but were strengthening the notion that the world is unreliable and unjust. This made the participants to be closer to their patients, their involvement in providing care for children and husbands made their relationships strong such that they would not want to leave them alone.

Wherever they would be they wanted to be with them rather than to leave the person with a stranger. Participants reported that the extent of the neurobehavioral consequences of TBI impacted their psychological well-being.

For spouse caregivers' responsibility was taken to be part of the marriage commitment as well as a sign of commitment to keeping the family together. They along with other family caregivers who participated in this study were clearly influenced by the large investment (emotional and affective) they had in their relationship with the survivor and they wished for some part of that relationship to continue.

It was evident, not only in this study, that family caregivers who had a patient with more severe TBI had larger burdens in caregiving (Livingston, Kennedy, Marwitz, Arango-Lasprilla, Rapport, Bushnik & Gary 2010:74) and had to take more responsibility for them. Responsibilities included helping the patients with basic daily tasks like washing, feeding, assisting when going to the toilet and bathroom (Kreutzer, Livingston, Everley, Gary, Arango-Lasprilla, Powel & Marwitz 2009:723).

The severity of the injury could give an indication of the potential responsibilities associated with the caregiver's role and therefore, also the stress load that the caregiver is experiencing as they could have this responsibility twenty-four hour without rest. This meant that some participants were sacrificing other aspects of their lives. Sacrifices included relinquishing things they were doing before assuming the role of family caregiver. These included sacrificing the aspirations of continuing with the studies and changing careers.
According to Jumisko et al (2007:354), caregivers spend less time doing things for themselves, especially as the recovery time is increased in TBI. All these made the participants to be uncertain of the future and they voiced their need for professional help. This raises a question on what can the brain therapists do to establish consistent, safe and reliable services that can ensure community involvement that can provide support and create safe environments for brain sufferers and their family caregivers.

5.2.4 Financial adjustment

Participants described many ways in which their lives were changed after the TBI patient was brought home. Some of the participants talked of the adjustments they had to make in their homes like making alterations to buildings and having some household assistance. Some had to change jobs they were doing in order to get better paying jobs so as to maintain a lifestyle they could no longer afford or maintain due to limited financial status.

The community contributions were mentioned with appreciation because in some instances they assisted with staying with children and some would provide food for those who could not afford. Other participants spoke of the fears and insecurities that accompanied taking on a new and extensive set of responsibilities as far as business is concerned because they did not have any training in money matters.

Some family caregivers, however, suggested that overtime they had found coping mechanisms in their lifestyle to accommodate the changes '*we take it one day at a time'*. One family caregiver even said that what she can tell people is '*that there is life after traumatic brain injury',* though there were still some behavioural changes that still evoked some sadness and anguish in family caregivers, particularly when they recalled how things have changed, how they used to be and what they have to endure in their caregiving activities.

Attitude seemed to be an important resource that helped the family caregivers in that if they stayed positive, being grateful and celebrating the smallest victories in the rehabilitative process, their anxiety levels would be lessened and as such improve their quality of life (Norup, Snipes, Siert & Mortensen 2013:80).

5.2.5 The gendered dimensions of family caregiving

Participants explained the stress of having to do tasks that were unfamiliar to them like bathing a man as they were culturally expected to shy away from a naked person of opposite gender. They felt that this lowers the patient's dignity and self-respect because sometimes the family caregivers have to request assistance from people in the community. Some participants were prepared to care for their relatives because they were complaining of the lowered standards of nursing in the healthcare institutions; they would rather stay with their patients where they would get all the love within their families.

Evans and Thomas (2009:111) assert that the privatisation of healthcare coupled with the deinstitutionalization of care inevitably increase women's unpaid care work within the family. This is due in part because in many societies the gendered constructions of caregiving posit it as a natural part of women's roles as nurturers or as a normal part of familial or kinship responsibilities. Moreover, because unpaid, informal caregiving is perceived as a low-status activity, it is often regarded as the sole burden of women as subjugated 'others' in the family.

Williams and Crooks (2008:243) argue that "caregiving has always been recognized as a 'women's issue', whether because it may happen in the feminized sphere of the home or because of social and familial expectations that construct it as women's work." Women's caregiving tasks in the family system include unpaid physical and emotional labour. Both categories of labour are reported to increase when the ill person is regarded as the family's responsibility, when the illness is chronic, degenerative or stigmatized and when formal and informal social and material support structures are weak (Evans & Thomas 2009:111).

D'Cruz (2004:413) explains caregiving as an activity that requires both the emotion of caring about, and the activity of caring for another person as emotional labour. The family caregiver has a caring motivation and his/her activity transmits to the care receiver the experience of being cared for both physically and emotionally. Hence family caregiving falls under the purview of emotional labour. Reay (2004) remarks on the development of the notion of emotional capital – seen as on par with Bourdieu's notion of social capital - to conceptualize the role that women play in relationships and family life in terms of affection, attention, care and nurturing.

Evans and Thomas (2009:112) explain that in many societies, care continues to be gendered as women's responsibility primarily because of the emotional labour of care work both at a societal and individual level. According to these authors, it is the gendered nature of emotional labour in the caregiving versus care-receiving relationship that speaks directly to social power relations embedded in affective relations. Thus, they regard caring practices and emotions in families as reflecting wider social, structural and gendered inequalities. Evans and Thomas (2009:113) speak of the relational nature of everyday performances of care and emotional work by women as embedded in dominant gender and generational power imbalances.

It can then be said that it often falls to women to do the emotional labour in familial relationships by becoming the caring, attentive, self-sacrificing caregiver. The consequences of such a one-sided burden on women to do the emotional labour is that they may suffer role strain and develop a false consciousness, denial and a loss of authenticity. According to Williams and Crooks (2008:320), these linkages are particularly apparent in caregiving in the family because:

- Such labour is characterized by complex emotions.
- Caregivers are often engaged in difficult caring tasks over an extended period of time.
- Familial care can be characterized by a strong sense of moral responsibility and empathic understanding for an ill relative.

- Informal caregiving at home may cause a disjuncture between women's sense of ideal homes and their lived experiences of the home as devalued site of care.

When discussing the physical demands of caregiving in resource-poor settings Evans and Thomas (2009:117), point out that gendered power relations may imply that there are conflicts that usually erupt between the needs of female caregivers and the family members in their care. Women are especially vulnerable not only because of their weak positions within labour markets, but also because within the highly skewed distribution of domestic labour most of the responsibility for parenting and caregiving falls on them.

Such insights are further explored by scholars working from a vantage point referred to as the intra-household bargaining framework. In this regard, Quisumbing and Maluccio (2003:283) theorize that households are not cohesive units, but instead sites in which individuals bargain over the allocation of resources. Moreover, bargaining power is influenced by the individuals' gender, age, and income, physical and social assets. For example, poor households may face severe challenges in maintaining food and livelihood security, with women having to give up regular meals or the opportunity to pursue paid work outside the home.

Moreover, frustrations over scarce resources spent on costly foods and medications may create intense feelings of anger, stress and isolation. In a study of informal family caregiving in Canada, Armstrong and Kits (2003:11) concluded that women were expected to take on home caregiving services without receiving pay or any other forms of compensation and at great personal expense to their own health, incomes, benefits, career development and pension accumulation. They concluded that while most women want to provide various kinds of informal care, they do not want to be 'conscripted' into this relationship. And the poorer women are, regardless of their culture, the more likely to have little choice about providing care.

When a person in a marital relationship suffers a TBI it changes the nature of their relationship. Spousal caregivers explained that TBI happens with a suddenness that is difficult to comprehend. They described how their biographical flow of their lives together as married couples were, in brief space of a moment, profoundly disrupted and indelibly altered. Couples had lost an implicit epistemology: of self, of how to be together and of a taken-for-granted way of being.

Being one's husband caregiver disrupts their relationship to a role more befitting of a parent than that of a spouse and as such a structural skew developed in their relationships. What developed was a dysfunctional spouse as controlling parent versus spouse as rebellious adolescent type of a relationship. The spouse of the person with TBI becomes alone and in many instances the closeness experienced before has completely changed. The spouses have to share their emotions in solitude. They no longer expected emotional support from their partners with TBI. Due to the effects of TBI such as tiredness, spouses experience the loss of companionship in their relationships as their partners would go to bed earlier and when the other goes there he is already asleep. The participants were in predicament situations because the continuum of normalcy in the relationships they had constructed for themselves no longer existed.

The continuums were constructed around ideas of an ideal father who would connect with his family, enjoy their company and provide a sense of security. They had notions about how good fathers play ball in the yard and spend time with their children. The families to return to their previous lives were strongly influenced by cultural messages about the normalcy and operations of social control.

As it was mentioned that Xhosa cultural norms are structured along patriarchal lines of power that require men to financially support the family, the family systems theory prescribe that when the husband is unable to provide for his family because of ill-health, the family system assigns other authority to intervene in order for the part of the system not to suffer.

All the participants who were caregivers to the husbands were staunch Christians so they were aware that a home is a home by having a father as the head of the family. Some were having feelings of safety and were confident as they would regard God as their head of their families. The incidence of TBI in their families forced them to confront issues of mortality and the inevitability of their physical demise – issues that are usually relegated to later in life – and to have more and deeper relationship with God.

Previously held frames of reference built on underlying belief systems, values and experiences were no longer congruent with the participants' current life experiences. Their ideas about the normalcy and moral obligations constrained the participants' narratives and did not open up possibilities for new frames of reference that promoted personal agency. For instance, all married family caregivers felt social pressures to maintain their marriage vows for religious and social reasons.

The spouse of men with brain injuries can neither divorce with dignity nor grieve the loss of their spouses because the familiar body remains and he is still loved in spite of the infirmity.

The married women participants were disciplining themselves to stay in their marriages that have drastically changed with men whom they no longer identified as their husbands and who often behaved in ways that were incongruent with their previously held joint values, citing reasons for staying as pity for the husband, for the sake of children and having nowhere to go. The researcher identified that the participants were still holding on to hope that their husbands would be able to reassume their roles as husbands and heads of their households as before. These notions have grave implications for therapy.

Participants described how they sometimes were like dealing with new babies. They had challenging responsibilities of caregiving an adult as if he/she was a baby. Some talked about having to constantly monitor the patient to prevent injury - *if in the bath he should not close the door in case he falls.* Sometimes they assisted them in relearning communication skills like relearn speech and social skills. Due to loss however, a non-death loss, the family is left with a feeling of mixed emotions of loss and gratitude that at least the sufferer has survived, but when the post injury characteristics seem to persist frustration ensues due to lack of information about the condition, knowledge and support/care for the family caregivers and family members in general.

The family has to contend with the loss of their loved one and the effective replacement by a ‘different child’ who has changed, physically, emotionally psychologically and socially. Family caregivers explained that they had to abandon many things that matter to them like loss of time to attend church gatherings since the patient came back home. One even wished the siblings of her mother could come to visit as she could not attend school and as such was anticipating registering with a distance learning institution.

5.2.6 Lack of information

To the family caregivers, traumatic brain injury was experienced as a vague concept and they needed some information. Participants could not explain what TBI is but would say it is a serious injury and the researcher would wonder whether this was referring to the serious physical injuries or to the more cognitive and behavioural effects of TBI. Some of the participants had been fortunate to have seen somebody suffering from TBI or having at least one person with the knowledge about brain injury with whom they could share their stories.

One participant commented on how TBI was a new concept to her. It is the researcher’s view that TBI brings about great change in the lives of family members and that having good knowledge of TBI would help them to understand their new world they have become a part of.

Initially family caregivers of patients with TBI were concerned about the visible scars from the injuries that their patients had suffered ‘she was shaved on one side of the head and was so oedematous, we hardly recognized her’. As time went on they worried about the extent of the internal injuries as cognitive and behavioural effects are often longer lasting. They wanted to know what residual effects TBI would have on their patients. It is accepted that parent caregivers will worry about their children regardless of their age.

Studies such as those done by Hay, Fingerman and Lefkowitz (2008:101) explain that anxiety and worry is relatively common in a healthy parent-child relationship. It is argued that they have to balance fear and hope in order to mobilize themselves to carry on. Family members find it difficult to cope and go into survival mode. They are scared and are left feeling unable to express what they feel.

It is suggested that the family caregivers need to continually identify and manage perpetual symptoms relating to the initial neurological incident. The prospect of a second injury incident has been shown to exacerbate the feelings of worry and uncertainty as reported by the parent caregivers.

In this study the aging process and physical weakening of the parent caregivers further added to the strain and exhaustion experienced by the caregivers. In a study by Hay et al (2008:127) they suggested that parent caregivers’ anxiety is not related to physical and mental health only but they are concerned about their adult child’s relationships and finances as well. These concerns have been alluded to as the parent caregivers explained their concerns on the negative impact of TBI on their adult children regarding their health, safety, relationships and finances. The inability of the patients to independently manage the above is shown to exacerbate the anxiety and fear reported by the family caregivers.

It is the opinion of the researcher, therefore, that traumatic brain injury is further complicated by not knowing what to expect in the process of the injury, sadness and fear that leads to anxiety. Anxiety may have a profound effect on the family’s daily coping because in some cases it continues for a long time without any hope that things might change.

People in traumatic circumstances have a need to hope or have an expectation that things will improve but they should be realistic that in dealing with TBI things may not become better. It is suggested that access to appropriate information and services particularly on the long-term caregiving needs, may reduce fears of the caregivers.

According to Laroi (2003:175), the need for information giving must not be ignored in favour of the therapy programs and focus on the injured individual, families need to be educated and reminded that many of the problems experienced by the individual and the family are physiological. This implies a process that takes place over a long period of time, not merely in the acute phase. He further cautions that therapists working with families must be aware of the different reactions - reactions that can be expected as a result of brain injury - those that cannot be directly attributed to TBI but can be seen as normal reactions to the event and finally reactions that are not related to the event at all.

Falk, Von Wendt and Sonderkvist (2009:125) suggested that studies investigating families' perceptions of information provided relating to their children with TBI showed that parents who received correct information at the right time were found to be less anxious and were more prepared for any eventualities post discharge. Sometimes communication difficulties may be exacerbated by the South African diversity of languages and cultures.

Although it is important for relatives to get information about the patient, O'Callaghan et al (2011:223) suggest that the healthcare professionals report that although it is important to provide family members with information, they are justified in the vague nature of that provision, given the uncertainty about the clinical evolution of the casualty as well as worries about upsetting the family unnecessarily by creating unrealistic expectations.

This perception of health professionals is incongruent with the Patients' Rights Charter as stipulated in the Constitution of South Africa (South Africa 1996) and Batho Pele principles where it is stipulated that patients and their families have rights to information about their healthcare, information about which hospital staff member provides their care, which means that information should be made available all the time so that they prepare themselves for any eventualities and the information should be free of jargon.

According to these principles, information should be in a variety of media and languages to meet the differing needs of different customers which is essential to ensure inclusion of those who are or have been previously disadvantaged by physical disability, language, race, gender and geographical distance.

In this study family caregivers thought their anxiety could be relieved through access to support services, the provision of more information, increased staffing in order to provide services needed by TBI patients, improved monitoring following discharge from hospital based rehabilitation services. According to the results of the study by Lefebvre, Pelchat, Swaine, Gelinas and Levert (2005:586), adults with TBI and their families were content with services during the acute care and inpatient rehabilitation phases, however, their degree of satisfaction/contentment changed when they returned home and they cited this to be related to lack of resources.

From the research findings of this study it was noted that family members felt traumatized to see their family members intubated, being swollen and having behavioural and cognitive limitations. The pictures they had of their relative in machines stay with the family members for a long time and work in their subconscious minds for a long time. By the time the patient is discharged all the emotional resources are already drained and depleted whereas this is the time they need them most.
They felt their future plans were disrupted and they could not plan and carry on without knowing what was going to happen. They had no control over the situation and their hopes were sustained through communal prayers and assistance from the friends and colleagues otherwise they fluctuated between despair, hope and anger. When they saw progress even if it was ever so little, it helped them to feel hopeful for the future and this hope kept them going.

Most family members may not recognise what the family caregiver is going through and may expect more from the latter. This makes the caregivers to feel pressurized to carry on without the family support as sometimes there is no reputable person to assist or take responsibility due to family dynamics. It is, therefore, suggested that information should be made available to family caregivers at any point during the recovery process.

This can be achieved through the use of support groups, church gatherings and multimedia resources like videos, WhatsApp and brochures. The path of information required should be in a dialogue. Healthcare professionals working with families who have been affected by TBI need to gain information about both the caregiver and the injured patient. In a study by Cecil, Parahoo, Thompson, McCaughey, Power and Campbell (2011:1723) it is stated that it is important to understand what the caregivers want to do and what they expect health professionals to do for the patient.

5.2.7 Lack of rehabilitative care facilities

A lack of acceptable care alternatives and negative experiences with the healthcare 'system' may well have been a contributing factor to some family caregivers' strong belief that home was the best healing place and family the best caregivers. Not all were as accepting of the concept of home as the best path to recovery with some citing the difficulties they were dealing with as far as family relatedness was concerned. Some stated real reservations about having the recovered patient return to their home after hospitalization.

As explained earlier brain injury is a family matter, therefore, rehabilitation should be a family matter. In order for individuals with TBI to achieve the best recovery possible, it is helpful for the extended family to provide assistance with everything including the activities of daily living (ADLs) and other activities such as advocacy and cognitive rehabilitation. In this way family members functioning has the potential to influence the outcome of individuals with TBI because the family members are often primarily responsible for assisting them in their recovery (Sady, Sander, Clark, Sherer, Nakase-Richardson & Malec 2010:1543).

According to Rivera, Elliot, Berry, Grant and Oswald (2007:30), there seems to be a relationship between family members' ability to adapt and cope with the demands of caring for a loved one with TBI and survivors' success in rehabilitation. Conway, Boekel, Shuster, Wages (2010:128) suggest that healthcare practitioners working with families need to identify families with difficulties relating to caregiving. They state that therapists should be involved in the development of appropriate intervention strategies for assisting families who are struggling with the issues related to caregiving.

The healthcare professions should expand the concept of what constitute a family and not only restrict it to nuclear family but to extended family as a care resource in our multicultural and multi ethnic societies (Bohman, Van Wyk & Ekman 2009:446)

It should always be remembered that families in this study are from previously disadvantaged communities. The contention here is that something befitting these communities should be suggested with the hope of making healthcare services effective to them. In the Eastern Cape especially the eastern part of the province which is called Transkei the rehabilitation and retraining services are in the referral hospitals only, therefore, making it difficult for patients and families to be assisted to return to their independent and productive role in the society because they are unable to go to such hospitals after discharge.

Most participants responded by explaining that their patients were not receiving any rehabilitation because of different causes, like they did not have money to spend for private health services and had no money for travelling to referral hospital; otherwise they would appreciate such services. Smith et al (2008:594) suggest that family caregivers are supposed to be an integral part of the rehabilitation team and yet there is no consistent approach to support or involve them in the rehabilitation process. This may be partially due to the limited availability of information concerning caregivers' specific support needs during this time.

The researcher is of the opinion that rehabilitation should be seen as a critical intervention by healthcare providers as it is aimed to ease the transition of patients and their caregivers into new roles within their families and communities and in facilitating the adjustment to the changed roles on the part of other members.

These services can enhance coping mechanisms of the family caregivers as well as receiving family therapy/education as most participants did not know much about TBI. This would help the family caregivers to also develop realistic expectations and improve their caregiving skills. The government and the private hospitals should address the issue of turning patients away because they do not have money as this could cause people to die or be disabled when they could have been assisted. These services should be made available even in rural hospitals.

The participants in this study expressed their need for practical training regarding care of patients with chronic conditions by the healthcare professionals so that they can know what to do when they need to help their patients. This idea is echoed in the studies by Cecil et al (2011) and Falk et al (2009). In the South African context discharging of patients from acute care or rehabilitation settings is frequently rushed due to lack of resources, human and financial.

According to Kreutzer, Stejskal et al (2009:535), this is an international trend though, because they state that shortened hospital stays necessitate a greater hospital focus. Some participants mentioned that they sought treatment from alternate health professionals when conventional or traditional medical interventions seemed not to help. In a study by Soeker, Wegner and Pretorius (2009:138) on patients with back injuries, participants mentioned that they found treatment from different sources such as chiropractitioners and psychologists in addition to the conventional physiotherapy assisting in alleviating their pain symptoms.

Faith also played a role in most of the participants' lives and gave them hope for the future. Most participants relied on communal prayers brought by colleagues and friends which according to the participants, brought them strength and hope. Religious practices such as prayer reportedly has significant effects on psychological well-being and overall functioning of the body and can act as a buffer in stressful situations (Joshi, Kumari & Jain 2008:345).

Department of Health should consider involving such practitioners as well as indigenous healers because some participants who believe in cultural issues saw TBI as having been caused by other influences. If such healers can be taught about TBI and be used to teach patients and their caregivers as they come to them for treatment, in return, their education can be acceptable to African families than that given by Westernized healthcare professionals.

5.2.8 Change in family generational structures

The fact that some participants took over caring for their grandchildren when the parent was inflicted with TBI did not appear to be an issue for them instead they welcomed being of help to one of their own. Changes in some family structures did not necessarily occur on some families because of the injury.

In South Africa especially in rural African communities it is a norm to have grandparents staying with their grandchildren and treating them as their children. Some would have grandchildren during holidays only but when there is TBI event they come and stay with grandparents and this may mean 'indefinite shift' in the family structure and added load to aging grandparents. The grandparents had to take over rearing of grandchildren having to contend with homework and abandoning their leisure pastime.

The role change especially with wives being caregivers caused more stress when it came to child rearing on their own and at times it was very difficult. They said when things get tough or there are problems to solve in the family, the person with TBI is not able to take initiative in any. All is left to other members of the family as the family caregivers sometimes have a need for assistance for certain tasks but in many instances there is no support available from the husband. The study also discovered that family structures changed after the brain injury particularly due to changing demographic and cultural aspects of families (Celdran 2010:203).

Some participants explained that when their adult children were discharged from hospital they had to be accommodated in their parents' homes because they required constant care and supervision. It is important for the healthcare professionals to gather information regarding the family structure, family members' roles and how the system functioned both before and after the incidence (Yeates, Tailor, Walz, Stancin & Wade 2010:345).

Conway, Boeckel, Shuster and Wages (2010:141) also suggested that 'learning about the family structure and the family dynamics could enhance identification of families at risk and more appropriate interventions can be made to meet their needs. It is the researcher's opinion that therapy plans that are specifically tailored to meet the needs of the specific individual patients and their family members are to be based on information gleaned from family members during caring and rehabilitative process.

It is also imperative that the healthcare professionals are aware of the family dynamics especially of the family caregivers and what effects do those dynamics have in caregiving and the family system. Several studies describe important unmet family needs in relation to caring for an individual with TBI.
Kreutzer et al (2009:536) identified the following as having an influence in the provision of care by family caregivers: not having a friend who has gone through similar events to relate to, no one to aid in conquering worries or preparing for worst care scenarios, inability to escape responsibilities, not knowing how to handle family members in stressful times, not being understood by family members who are not providing care and not having help in completing household duties as specific unmet needs of family caregivers of TBI. These relatives who have hands-off-attitudes towards family caregivers are quick to offer sharp critiques of how the immediate family is doing.

Though there may be this animosity the rural communities and families have social cohesion which is still strong. This may be due to the fact that families in the rural community is characterized by intergenerational relatedness where you find certain families being related to each other in some way even if it is a distant generational relationship.
The researcher decided not to extend the scope of this study deep in exploring the marital relationships in TBI but it should be addressed in future research studies. The partners or spouses who were family caregivers were unable to cope with the demands of caring for a TBI sufferer and care for themselves as well. The researcher is of the opinion that conversations with these partners in future therapeutic sessions could open up possibilities for going on with life rather than giving up.

Family caregivers could have social support through social networking with other people who are caregivers of patients who have been rehabilitated after traumatic brain injury. White (2008:390) refers to this concept as exploring other territories or regions of living. Social networking entails extending family and social systems to identify and solicit resources that can strengthen family functioning and/or assist in the care of the brain injured patients.
An extension of this intervention could be to establish community halfway houses manned by volunteers, rehabilitated TBI patients and their families. Family caregivers

could be able to leave their loved ones with such volunteers for a weekend or a day at a cost, when they need a break. These services could be ideal for rehabilitation services or occupational health even the social workers and psychologists could have access to these people rather than being unable to reach them due to bad road and unavailability of transport to go to rural areas. Open door policy on the side of the healthcare professionals should be practiced in order to promote consultation by patients and their caregivers.

5.2.9 Family caregiving experiences

According to Le Dorze, Signori (2010:1073) and Natterland (2010:19), the studies on experiences of carers of spouses and children who have suffered neurological injuries may not differ that much because mainly their problems emanate from changes in communication patterns, role changes and changes in responsibilities within the family. Studies show that accurate communication amongst couples should be maintained vibrant to maintain a good relationship as an expected element to ensure marital bliss. Threats (2010:451) suggests that the partner of a TBI patient can be viewed as the ‘hidden victim’ in the relationship.

The above suggestion is similar to the findings of this study in that the family caregivers may be regarded as hidden victims following their next of kin’s neurological event. because their needs are disregarded and they complain because of fearing to be seen as noncompliant. According to Lester and Glasby (2006:211), the caregivers of people with chronic conditions are the silent partners in community care because they have become so used to the difficulties associated with caring and with the lack of support from formal services that they see this way of life as a norm and do not ask for help. The two authors suggest four characteristics of the caregivers that are often overlooked, namely:

- Every caregiver faces distinctive caring responsibilities and thus has particular support needs. Thus caregivers cannot be classified as a homogenous group with a shared set of needs.
- Caregivers are not trained in care giving and so have no knowledge of traumatic brain injury.
- Caregivers do not always want to take on the care burden, but have no other recourse.
- Caregivers have a low ceiling in terms of demand for services and thus they are not a group to make unrealistic demands.

The participants in this study explained that all the patients who had suffered traumatic brain injury were having cognitive-communicative difficulties and this had a negative effect on their interactions and subsequently their relationship. The researchers have suggested that the appointments of formal paid caregivers may offer respite for burdened caregivers (Casado, Van Vulpen & Davis 2008:29). These have shown that formal caregivers may be involved in providing medical and physical assistance as well as assisting in decision making in the care of the patient.

This may appear to be an ideal but the reality is that private caregiver services are very expensive in South Africa and they are inaccessible to a large percentage of the population especially those in the rural areas. Besides that, as it was mentioned by one of the participants, neurological patients sometimes do not want to be nursed by strangers and tend to be violent causing the people that have been engaged to assist to leave especially if one does not have tolerance and empathy. Sometimes such caregivers may be taken as part of the family and expected to provide services which fall outside of their professional duties (Sims-Gould & Martin-Matthews 2008:1573). This results in negative reactions on the part of the family when there is resistance on the part of the caregiver.

Factors influencing the choice to provide care in one's own home are under investigated, however, some researchers have commented on values similar to those found in this study that shape caregiving experience. Family caregivers typically maintain 'rescaled' priorities characterized by putting the survivors' needs first for a longer period and this affect their health reserves.

In this study, the preponderance of women being caregivers when their spouses were injured is understandable; given that men more frequently sustain TBIs than women in South Africa and besides that women are seen to be more resilient than men. In parental relationships with the preponderance of female caregivers warrants additional examination.

Outside of societal influences placing women in caretaker roles, another possible explanation is that women are more willing to share information about their experiences about brain injury than are men, hence many women than men may choose to participate in studies such as that carried out for the current research study. One explanation for this phenomenon is that the experience of sharing personal life events is more appealing to women than to men.

The experience of trauma subjects and leads the family system to have feelings of mixed emotions of loss and gratitude. Loss when they experience frustration due to the persistent post injury characteristics, lack of knowledge/information and support for their surviving family member. Family system would show gratitude that at least the person has survived the injury.

Due to the injury the participant’s role in providing support to their patients in their activities of daily living (ADLs) seemed difficult and limited because they used to be normal people who were able to make decisions, had analytic thinking and would not have been classified as mentally unstable in any instance before the injury. The participants were, therefore, having difficulties in advocating patients’ needs as compared to people who were born with the health conditions that require high support.

The results of the study resonate with the literature of what is a significant health problem, traumatic brain injury. It is clear from the themes that were identified in this study that its impact in the family system was modified by unique variables like the type of relationship dynamics before injury, coping mechanisms and other dynamics of the family like personalities and belief systems. With regard to the theory that has been employed in this study, family systems theory, it is clear that the families operated as an open system each member reacting and responding to inputs as a unit of the system and also had interaction with their environment. The inputs into the family system were acted upon and modified by the family.

This process is clearly defined by how the individual family members described the process of role redefinition and the personal sacrifices in order to sustain the family as a unit of interaction. There appears to be an exchange of energies and information between the families and their environment and the behaviour of each family caregiver is explained in terms of the individual’s relationship with the environment and the member’s function in the family. The families responded to the inputs about their new family environment after TBI and had thus adjusted their roles, responsibilities and expectations.

5.3 CONCLUSION

Perls (1973:17) once stated that no individual is an island or self-sufficient, the individual can exist only in an environmental field and is inevitably at every moment a part of some field. When considering the circumstances (Woldt 2005:160) of family caregivers, hostility, intolerance, conflicts, resistance, disagreement and unfriendliness seem to be the order of the day. An environment that is filled with constant disruptions without support means that the family caregivers may be faced with difficulties and challenges, just like it was reflected in the interviews of the present study.

During the interviews the researcher could establish that the family caregivers were discouraged to make contact with the environment, both internal and external. All the participants highlighted the need for support from families and health and related professionals. Though responsive meetings with healthcare workers (social workers, psychiatrists, nurses and doctors) would encourage their differences and voices to be heard, family caregivers seemed not to have any person supporting them - nobody from the environment seemed to support the responsive meetings something which led to difficulties for family caregivers. Some participants indicated their reluctance of making their needs to be known, so they had to suppress their needs not wanting them to surface owing to the fear of being viewed as emotionally not able to cope.

In the next chapter the model of support and guidelines to improve the lives of the family caregivers will be discussed.

CHAPTER 6

MODEL FOR SUPPORT OF FAMILY CAREGIVERS OF PATIENTS WITH TRAUMATIC BRAIN INJURIES

6.1 INTRODUCTION

In Chapter 5, the researcher discussed the research themes obtained from in-depth individual interviews conducted among family caregivers of patients suffering from TBI in the rural OR Tambo District Municipality of the Eastern Cape Province. The results were compared and contrasted with literature from other studies. In this chapter, the researcher presents a proposed model for support of family caregivers of these aforementioned patients. The model was also formulated based on the findings that emerged during the analysis of data and literature control.

Criteria of nursing experts who evaluated the model

The model was further subjected to evaluation by five (5) nursing experts who included specialists in critical care, primary health care and trauma trained nurses. These were clinical preceptors, nurse clinicians and nurse educators.

6.2 DESCRIPTION OF THE MODEL

A graphic representation of the model is presented in Figure 6.1 and is described using the following headings:

- Orientation to the model
    - Purpose
    - Assumptions
    - Context
    - Relationship statements
- Structure and process of the model
- Description of the model

6.2.1 Orientation to developing the model

With the recent change from the Millennium developmental goals to the new sustainable developmental goals there is a need for attention, on a broader set of social determinants. It has been highlighted that there should be specific sensitivity to equity in the provision of health services to ensure a substantial effect on health.

The researcher decided to include social determinants of health in the development of a model for support of family caregivers of TBI as there is need for a shift from a specific focus on health outcomes to a shift to evidence based thinking challenging purely the biomedical notions of disease process. Addressing the social determinants will ensure the success of Primary Health Care (PHC) reengineering strategy. Addressing the needs of the individuals on the PHC approach using intergovernmental process in order to strengthen society participation will ensure equity of healthcare service resulting in attainment of Health for All.

The family systems theory is based on the general systems theory. As discussed in Chapter 2, Von Bertalanffy (1968) stated that general systems theory attempts to integrate and create wholes out of parts as a science of wholeness. Its principles are based on observation that nature is organized in the patterns of complexity and comprehensiveness. Bowen (1985) argued that systems are a set of interrelated elements but that each of the elements is distinct from the environment in which it is embedded but all these work together to form a system.

Family systems is aimed at developing and formation of rules and principles that inform and govern cooperative behaviours and relationships within the family. Hannah and Brown (2004:45) view individuals, families and communities as systems interacting with and interdependent on subsystems, not living in isolation. When there is a chronic condition in the family the members of the family situation have to adjust the way they do things, in their workplace, change roles to conform or suit the new situation thus the boundaries of the environment are reshaped.

During the course of the study it was evident that family caregivers were providing care to one of their kin and did not perceive this as a burden as they felt that they had a responsibility to care for their relative. They were satisfied that they could assist especially when they knew that the relative was aware of what was being done for him/her though there were challenges that were being experienced as well.

The identified challenges faced by family caregivers in their provision of caregiving to TBI sufferers were taken into consideration/account in the development of the model. The study results confirmed that family caregivers are the key players in providing invaluable care to chronically ill patients at home. However, these people hardly receive adequate support from the healthcare practitioners and related services.

Humans are unique individuals and they each react to the environment differently from other individuals. Their existence is primarily in the experience of human kind and each individual exists in an environmental field with which he must engage. Though TBI patients were unique individuals, family caregivers, because of the inter-relationship and interconnectedness identified with the patient such that they sacrificed to give care to the afflicted in order to bring equilibrium to the environment.

In a systems model an injury to one part of the system means all parts get affected hence the family therapy approach of utilizing families and making them to adopt a more prominent role in a patient with chronic condition. She was reminded of the fact that even the most resilient individuals can experience vulnerability in a system that is not supportive, which means that family caregivers should always have confidence of support from different stakeholders in their environment. A conceptual understanding of the social determinants will be influenced by the interaction of the different social structures.

Ideally the TBI patients should be given care in their homes in order to promote acceptance by the community. The reality is that family caregivers do not have access to information regarding TBI and the healthcare professionals were not available to educate them on the condition. They did not provide the environment that was supportive for family caregivers to promote differentiation of self. Healthcare professionals should consider the potential of human beings for resilience and adaptability to the unfavourable environment. It is crucial for healthcare professionals to provide adequate support for the family caregivers in order for them to develop the desired competency in their caregiving.

The family systems model assumes that family caregivers should be in control of their environment and be able to make decisions in a variety of choices in order to make informed decisions. The ability of family caregivers to make knowledgeable decisions about their choices that impact on their well-being will enable them to actualize health that is sound and holistic.

The role of the healthcare professionals is to provide an environment that is conducive to support in many ways and acting as advocates for those who are voiceless. The healthcare professionals should integrate their services with other members of the health team and other social structures in order to provide comprehensive services taking into consideration that patients have intergenerational relationships with their families so the services that are provided should be congruent with the family background taking into consideration that it is the contact between the person and the environment that defines his identity. According to the proposed family systems theoretical model family caregivers will be guided to wholeness if their interaction with other systems within the environment is positive so that they can develop strategies to adapt to stressors.

6.2.2 Purpose of the model

The aim of developing a model is that it could be used by healthcare professionals and societal stakeholders locally, regionally, provincially, nationally and internationally in the support, care and treatment of family caregivers. The model is to equip, support and motivate the family caregivers of TBI patients with the knowledge and skills. The structure of a model refers to overall organization of the model, how ideas and concepts are represented and the linking between the different concepts. Chin and Kramer (1995:112) state that theory structure depicts the overall form to the conceptual relationship. It also refers to structural presentation and the process of the model in this instance the need for support of family caregivers of TBI.

A nursing model is, therefore, a collection of ideas, knowledge and values about nursing that determine how nurses work with their clients. According to Slevin (1999:188-200), a model reflects an attempt to provide a general conceptual framework that in turn enhances an understanding of the situation and guides practice within the framework. It has to define what is to be done, how to do it and how to evaluate it.

During data analysis the researcher identified some challenges that family caregivers were experiencing. The health professionals were neither providing any support strategies to relieve them nor attempting to provide a conducive environment for self- development and relief during challenging times.

In systems theory all the stakeholders of the health system – professional practitioners, patients and family caregivers are supposed to be always in interaction, affecting and being affected, with the environment adjusting and adapting to the situation until they reach equilibrium.

6.2.3 Major concepts of the model

- **Interaction**

Interaction refers to the communication between systems, which in this study refers to family caregivers, patients and professional health/social care providers. These systems interact in order to determine goals and the means to achieve them as transactions. Part of the interaction is the exchange of information in order to ensure an acceptable level of care, verify the accuracy of the information, assess the situation and work out the problem solving strategies.

In interaction between the patients, family caregivers and healthcare professionals, the input from each individual is influenced by one's value system and cultural background that each bring to the interaction. In order for positive communication to occur interaction should occur at different levels in the environment.

- **Differentiation of self**

This is defined as the degree to which one self-fuses or merges into another self in close relationships, self in this context meaning the ability of one adhering to one's own principles and goal directedness no matter the amount of pressure or anxiety one is experiencing.

A person with a well differentiated self recognizes his realistic dependence on others, but he can stay calm and clear headed in the face of conflict, criticism and rejection to distinguish thinking rooted in a careful assessment of the facts from thinking clouded by emotions, but if one does not have enough self to accomplish his goals one manipulates his way by mechanisms like bullying and guilt.

The challenge of becoming a functional individual is to develop a self that is able to hold one's goals, beliefs and values while respecting those of others and without being emotionally determined by the pressures of the family system. In order to provide quality care and an environment that is protecting, enhancing development and well-being, caregivers assume different roles exhibiting different qualities

- **Family**

A family is considered as a system since it fits the definition of a system being comprised of different individuals and generations from each individual's background. It is seen as being a stable basic structure of the society that depends on certain variables which also have to stay within the defined limits. The behavior of each individual within the family is perceived as related and dependent on the behavior of all other members of the family.

All behavior is considered as communication and it therefore, influences and is influenced by others. Change for the better or worse in a family member who is identified as a person who has acquired a sick role in the system will have an effect on other family members psychologically, socially and otherwise.
Some families are able to absorb large setbacks and even turn them into rallying points while others are unable to handle even the most insignificant crises.

The systems theory understands the family as an emotional unit that has an ability to include in the concept of "family" all generations of the family, both living and dead. It further allows insights into family relationships from a biological and evolutionary perspective, with a focus on those relational processes that all humankind, share with other species. It is regarded in terms of an on-going, constantly changing process, where all things are inextricably linked and part of a network of interactions and thus subscribing to holism.

- **Holism**

Organisms, the world, and life itself should be perceived as undivided, and as greater than the sum of their descriptions. According to Ginger (2007:2), holism refers to the concept that the whole is greater or different from the sum of its parts. This theory is an integrating concept which strives to bring all parts of the field together – "person and situation, self and others, organism and environment, individual and communal" (Parlett,1997:16). It assumes that all things are interconnected and that the organism and the environment co-regulate one another.

Change of the organism takes place as a result of interactions at the boundary of the environment field. Some families only operate according to one model while others exhibit characteristics of them all. The degree to which these families adhere to these patterns in order to assuage anxiety determines their ability to function in holism.

Nurses are best suited to provide support to patients and their families as their basic education program for being professional nurses is based on the tenet of holistic practice. Nurses are to provide holistic nursing care to all people irrespective of colour or creed. Holistic care includes provision of healthcare which encompasses the whole man, physical, psychological, social and mentally within the cultural pattern in which one was born and to which one attempts to conform.

- **Caregiving**

In this study, caregiving means the provision of care within a person's homestead, which includes specific caring characteristics like understanding, availability, respect, empathy, provision of hope and physical support. For caregivers to exhibit such characteristics, caring should occur in a supportive environment free of stressors but with plenty of motivation so that they can be innovative in their caring and be able to learn new behaviours. They must feel free to participate in the decision making process of their healthcare.

Caregiving in this study was done by family members who were assigned the task of being caregivers either by virtue of being the only one who could do that as far as familial assignment is concerned or through volunteering to do so. The family caregiver might not have had prior experience of caregiving to a person suffering from TBI or any chronic condition. This would make the type of care given to be riddled with mistakes and stresses hence the need for professional support.

Caregiving for TBI patients is very demanding for family caregivers and healthcare professionals as well.

Nurses have to create good relationships with the family caregivers as well as the other members of the family and health team which does not always occur because of the dynamics of the environment.

- **Support**

Support may be defined in many ways and the manner in which it is intended for health professionals is multi-faceted. It reflects the activity that the health professionals provide. It requires cognitive, social and emotional skills that may or may not be present. It has the notion of propping up already existing information that family caregivers might have. Support also implies the assistance with maintaining positive strategies to improve desperate situations. According to Larkin (2006:53), support is generally perceived as encouraging, enhancing psychological well-being, feelings of being in control and a good self-esteem whereas the absence thereof may contribute to factors such as loneliness, depression and despair.

Support in a long-term or chronic conditions need to be sustained and maintained in many forms. Medical doctors and other health professionals may not have such necessary skills as these have to be learned and developed during the period of one's becoming. Support will also regard the psychosocial and affective aspects of care. In this study family members preferred to be visited by nurses because they appreciated the fact that they displayed affective aspect of care.

Nurse practitioners are better suited for this aspect, therefore, family caregivers should be encouraged to seek nurses for resource and support in healthcare. If caregivers were to receive training and support, feelings of preparedness might be experienced. As alluded to above, the family caregivers were placed in a caregiving environment, without any prior training, to identify and support people inundated with trauma symptoms. Caring for challenging patients who show problematic neurological symptoms complicates the caregiving role (Boyd-Webb 2006:58). The researcher was motivated to develop a model for support of family caregivers so as to empower them in their caregiving role.

- **Environment/context**

According to the *Collins English Dictionary* (2014, "context"), context refers to the conditions and circumstances that are relevant to an event, fact, etc. It can also be viewed as the setting or the circumstances in which an event occurs. According to Watson, Broemeling, Reid and Black (2004:1), contextual factors such as social, cultural, political, economic and physical environment influence health service delivery in the community.

Context, together with the input from the environment directly determines the output of health service activities. The environment and being human is considered a totality where "meaning derives from looking at the total situation, the totality of co-existing facts". This totality (holism) includes all aspects of the environment and the organism.

The environment of this model was the OR Tambo District municipality in the Eastern Cape Province. The community in which the study was undertaken is considered one of the most historically disadvantaged communities judging by their poor state and the conforming of the families to tradition and culture.

Critical care nurses were the first point of entry to healthcare for family caregivers in this study perceived in high esteem by most participants because they were the ones that were supportive to families whilst the patients were still admitted and they would be seen regularly in the communities. The fact that they could not provide them with medication was not seen as their fault. They were rather seen as protective factors and being key to the creation of an enabling environment in their situations.

The family caregivers gave various issues influencing them in even understanding their family members suffering from TBI. The feelings cited by family caregivers included shock, despair, fear, uncertainty about the future of the relative with TBI and frustration with care rendered to their family members in hospital.

They were worried about the situation in which they found their relatives in hospital. The change observed in various family members in terms of mental functioning was also a cause of concerns from many of them. They also expressed a number of needs as caregivers in their endeavor to ensure that the care of their family members suffering from TBI is rendered appropriately in the home or hospital setting. These included issues like the quality of their relationship with the care providers and community integration for their patients.

According to Guishard et al (2007:28-29), protective factors are those external and internal resources that limit our vulnerability to long-term psychological problems. These may be the family, society/community and genetic framework.

Critical care nurses are, therefore, fundamental in the family caregivers' endeavors for holism, contributing in building an environment that provides protection, development and well-being of TBI patients.

6.2.4 Relationship statements of the model

Based on the provided concepts above, the following relationship statements are proposed:

- The family caregiver as the most important person in the environment interacts with the critical care nurses, the family and the communities as the relationship unfolds during the problem identification phase.
- All persons that are involved are social beings who interact with their environments, internal and external, in a bio- psychosocial manner thus causing change in others' environments through their patterns of interaction.
- Every human being forms relationships in his environment and integrates with other human beings in order to have control of the environment through use of perceptions and instincts.

- The relationship between the health professionals and the family caregivers remains the primary relationship. The family and the community stakeholders are involved as they are identified during the problem identification stage.
- The more constructive collaborative interaction between all parties, the better the facilitation of wholeness and support of the family caregiver.
- The resultant feeling of support will facilitate better and rewarding interactions with the patient, family and community.

The structure of the model is described below:

6.2.5 Description of the structure of the model

The model is drawn in a simple, classic and uncluttered manner though there are a variety of shapes and arrows used to show relationships and interactions between various concepts. The data analysis was used to conceptualize the clinical phenomenon of effective family caregiving in the context of this study. The data assisted the researcher in conceptualizing the model that could be utilized in empowering the family caregivers in providing care to TBI patients in a rural context.

The model portrays the elements that are essential for providing effective healthcare to patients with TBI and support to family caregivers. The diagram of the model which denotes an environment as the major concept in the model has no line bordering it but has dotted boundaries so as to keep its boundaries flexible to change occurring in the systems. The background of the model is round to show that it has neither a beginning nor the end. This is typical of a family environment because it includes everybody, members of the unit family, extended families and inter-generations of families.

The systems that need to be in constant communication and interaction comprise of the personal system (family caregiver), interpersonal system (family members) and the social system which includes the rural/semi-urban community stakeholders, healthcare services, social workers and all non-governmental organizations. These have been drawn in interlocking elements to show that they are meant to interact with each other. Interaction between these systems is always open as depicted by the arrows that connect them together.

The family caregiver is the central circle within another circle which denotes that the individual belongs to a family within the community. The boxes on the sides of the circle are highlights the experiences/challenges/resources that will be mobilized by the healthcare professionals to remedy the plight of the family caregivers and to maximize the environment's potential to be supportive to family caregivers and their families.

South African Government policy supports an interdepartmental approach which involves relevant non-governmental organizations and the corporate sector willing to assist in providing respect and appreciation of human worth.

The pink diagram denotes the professional nurses and the multi-disciplinary health team which includes physiotherapists, occupational therapists, psychologists and social workers etc. The nurses are the leading professionals in this group as they provide PHC in the clinics and are the ones who do home visits in the community settings.

The black coloured shape denotes the concept of 'inability to cope' of family caregivers. This is a central concept because it is the cause of instability and disequilibrium in the family structure as well as the community.

Because the caregivers are in distress they have feelings of being alienated by the other members of the family and communities. They therefore need to be recognized as human beings doing a respectable function in the community. They want to restore the sense of being dignified human and social 'beings' within the family systems in their communities. Healthcare professionals can play a facilitative role in ensuring that the feeling of wholeness is achieved.

The red diagram denotes the unavailability of resources that need to be mobilized by the professional nurses to maximize the environment's potential to be supportive and ability to empower the inflicted family caregivers, families and communities. It also reflects the lack of infrastructure that the family caregivers have to contend with in the district of O.R Tambo where they cannot be able to have ambulances.

In the hospital setting there are no services that are specific for TBI patients and or specialists where they are referred to. The referral hospital has no specialist neurologist but doctors who are experienced in treatment of neurologic conditions. The machines that are supposed to assist in treating patients are always non- functional and protocols are lacking as far as treatment of TBIs is concerned.

The pale yellow diagram represents wholeness which is the ultimate goal. In order to facilitate support of family caregivers, the critical care nurse should engage multidisciplinary approach to their care through constructive collaborative interactions in educating the family caregivers, patients and families to alternate their methods of expressing their emotions and feelings so as to achieve a supportive environment.

By having a supportive environment psychological, physical and emotional, holism will be enhanced. The acquisition of adaptation skills will promote self-enhancing potential of the people rendering them to be in control of their internal environment. The family caregivers, their families and the community will be better informed to deal with the cause of stress in caregiving and through enhanced interactions they will be attracted to each other and be willing to assist each other and providing respect and appreciation of human worth.

The arrow directed to the left is highlighting the challenges that the family care givers experience when caring for a TBI patient. The arrow to the right denotes that if the family caregivers can be supported by everybody in the community, including all the departments, by providing all the services needed in the rural communities, like accelerating services for social care and facilitating road maintenance in rural gravel roads, this can lead to communities gaining quality life even when they are living in formerly disadvantaged societies.

The green square at the bottom is placed in the context of being in control of the environment, enabling self-care. The family caregiver experiences feelings of renewal and no longer having fears in his/her interactions. One is now able to reflect on ones' feelings about the family and community without feelings of need for help.

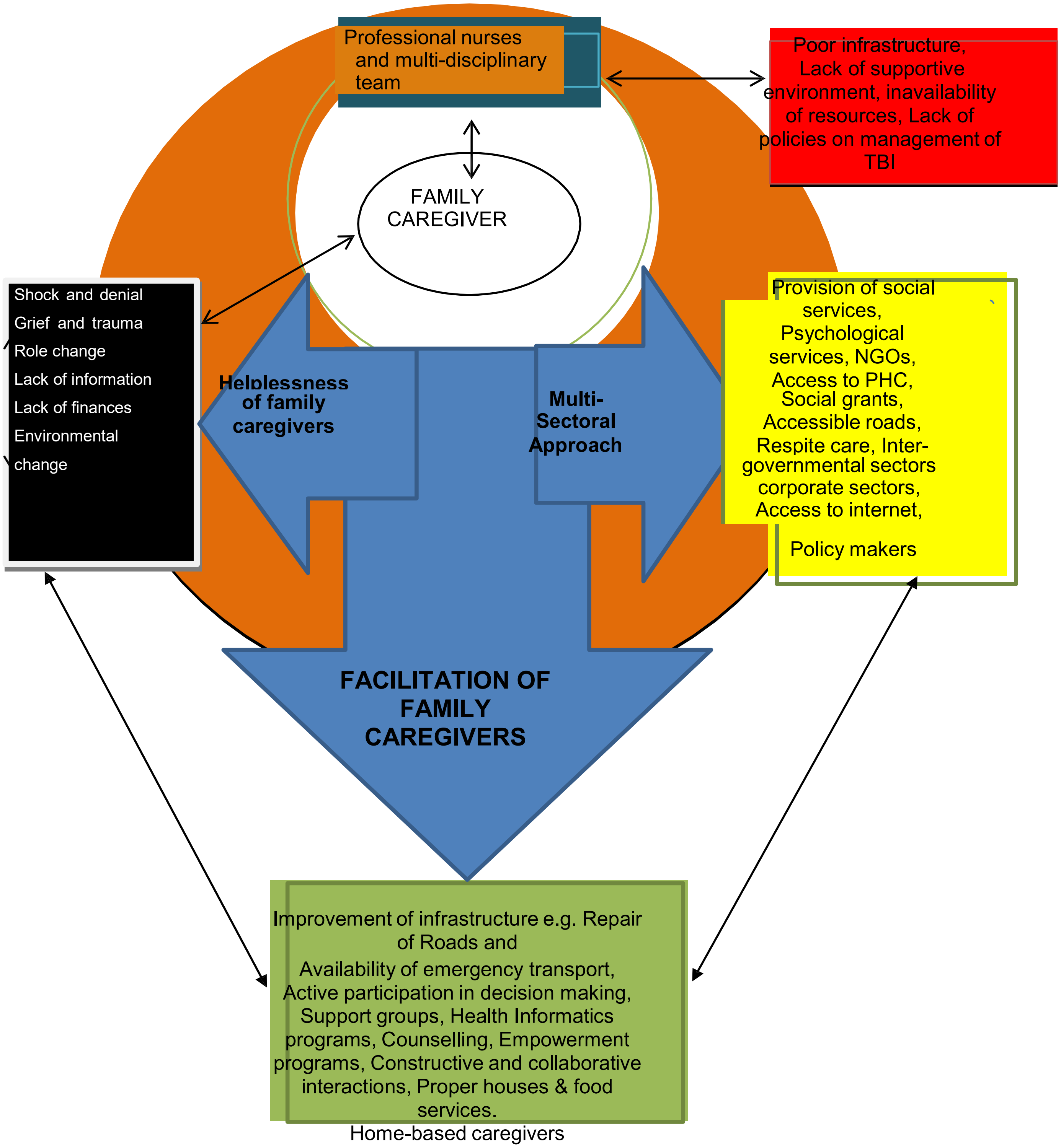

Figure 6.1 Model of support for family caregivers

- **Assessment**

The initial intervention is the stage of assessment and problem identification phase. This stage involves systematic and orderly collection of data from the family caregivers. According to King (1985:75), systems theory is useful for assessing individuals and groups relationships in nursing.

It can, therefore, be concluded that the systems theoretical framework is an appropriate tool for assessing the interactions between family caregivers, family and community particularly their responses to stressful situations and on how they adapt to them.

It can, therefore, be concluded that the systems theoretical framework is an appropriate tool for assessing the interactions between family caregivers, family and community particularly their responses to stressful situations and on how they adapt to them.
Assessment incorporates perceptions, communication and interaction of the nurse and the client who in this instance is the family caregiver.

A comprehensive assessment is a cornerstone of good practice in health and social care of TBI patients and their caregivers. The nurse needs to draw on information from generated theory, research and clinical practice. The experiences these people share involve life events, stressors and risk factors that result in a feeling of loss or place an excessive demand on ones' ability to cope. The systems approach enabled the researcher to take a holistic view of the family caregivers and their environment. This makes it possible to assess families' dynamics and how these affect others in their environment.

- **Nursing diagnosis**

This stage may be defined as the identification of human responses and resource limitations. It also addresses the clients' concerns and disturbances in the health system. The nurse's understanding and analysis of the patient's social system and their interpersonal relations are highlighted in this stage. Interacting models emphasise social acts and relationships between human beings.

- **Planning**

This stage denotes the determination of what is to be done to assist the family caregivers of TBI patients in constructing coping mechanisms and to maximise adaptive coping responses. In this stage the nurse and the client set goals and agree on the means to achieve them.

In this study the critical care nurse and the family caregiver design together a plan of action paying particular attention to promoting strategies of wellness attainment and maintenance in the face of problems that originates in client systems reaction to stressors arising in the external and internal environments (Neuman 2011:142).

- **Implementation**

After planning procedures and setting goals for the care of TBI patients all parties concerned start implementing the strategies in order to achieve the goals they set. The professional healthcare practitioners consider various actions and select achievable goals and objectives. These strategies will be directed towards influencing predisposing factors, stressors and coping resources available through health education and supporting social systems.

Health education involves strengthening of individuals through competence building to increase perceived control over ones' own life, effective coping strategies and an improved self-esteem. Competent family caregivers and the community are the people who know the available resources; they can make reasoned decisions about the issues facing them and can cope well with their problems.

The environmental change involves modification of the immediate environment through economic strategies like improvement of houses or family statuses. The recognition and strengthening of natural frameworks to which people belong, identifying social support networks that can be provided by the formal institutions within the community can provide intensive support for family caregivers and increase the knowledge base of community support systems and networks.

Evaluation

This stage involves appraisal of behavioural change after the implementation of actions by the professional nurse. The key to appropriately evaluate such actions lies with the plan when objectives are clearly stated in behavioural terms with clearly stated outcomes. Just as the goals and objectives should be mutually agreed upon by the nurse client it is important that the nurse and the patient set the criteria for the evaluation.

Input in a family systems model comprises the elements that move from the environment into the system. The family caregivers are the input entering the healthcare system from the community which is the environment.

Output is a product of the system. In this instance it will be family givers describing their satisfaction in the support provided by the healthcare professionals and the related organizations.

According to Watson et al (2004:3), in order that there is efficient service delivery and effective outcomes in the healthcare system, good relationships between environment or the context in which the health service delivery takes place, input (human, material, information), activities such as clinical care, and output (immediate result of activities) and final outcomes, which benefit both the individual family caregiver as well as the community, are necessary.

The external environment (social, physical and economic contexts) influences availability of resources (inputs), activities, outputs and outcomes. The level of participation and characteristics of family caregivers or community also influence the outcomes of health service activities.

- **Evaluation of the model**

The researcher adopted an analytic approach in developing the model. The model was evaluated according to the criteria of clarity and consistency, generality, practicability, flexibility and adaptability and appropriateness.

- **Clarity and consistency**

To ensure clarity and consistency in the model, the researcher tried to avoid unnecessary repetition when explaining the different concepts. Diagrams and illustrations were utilized to enhance clarity and understanding.

- **Generality**

The model must be general enough to be used in a variety of settings rather than one particular setting. This model is capable of laying a foundation for nursing research, and can be applied to individuals, families and communities in as far as the international communities.

- **Practicability**

The model can be implemented immediately as there are no cost implications. The model is useful because it enables the healthcare professionals to consider a variety of factors, and emphasizes partnership with all the relevant stakeholders relevant to healthcare. Active participation is necessary from all concerned so that the goals are mutually agreed upon. In this study, active participation of family caregivers in different platforms of healthcare was encouraged so that decision making would be made in consideration of a wide variety of considerations.

- **Flexibility and adaptability**

The model can be used in various settings in healthcare settings where there is a problem of inability to cope. The family caregivers and professional healthcare providers can use it for teaching, administration and clinical practice.

- **Appropriateness**

This model is intended for a specific target, namely family caregivers and professional healthcare providers. The model has used the nursing process of assessment to determine the problems of the family caregivers. Cooperation between the family caregivers and healthcare providers is encouraged to solicit input from the professional health providers. Healthcare consumers are to make informed decisions on their health.

6.3 GUIDELINES FOR OPERATIONALIZATION OF THE MODEL FOR SUPPORT OF FAMILY CAREGIVERS OF PATIENTS WITH TBI IN THE RURAL O.R. TAMBO DISTRICT MUNICIPALITY OF EASTERN CAPE PROVINCE IN ORDER FOR THEM TO ACHIEVE WHOLENESS

The proposed guidelines for the operationalization of this model will assist health professionals to be more effective in supporting and nurturing the health and wellness of family caregivers in the rural OR Tambo Municipal District. Families often share a unique history and investment in their relationships, caring for each other and promoting the welfare of family members. This can be especially true when a family member is faced with a serious challenge such as traumatic brain injury, which often results in family members becoming caregivers.

The caregiving role can be very challenging; the episodic and sometimes unpredictable nature of many TBI, its chronicity and lack of knowledge about it can present challenges for family caregivers.

Compounding these challenges, caregivers often have to deal with the stigma associated with mental disability as traumatic brain injury most commonly manifests itself by aggression and convulsions. Despite these challenges, many family caregivers persist in attempting to fulfill a distinct and important role for their family members by sacrificing themselves to provide support and caregiving, advocating on behalf of the person and contributing to his or her recovery.

Family caregivers especially those in the rural Eastern Cape need ongoing guidance, support and access to information, to fulfill their caregiving responsibilities effectively and to minimize the risk to their own health being negatively affected and compromised hence the formulation of guidelines for provision of support.

- **Purpose of formulating guidelines**

The purpose of formulating guidelines is to advise system planners, policy makers and health managers in planning, implementing and evaluating a family-friendly system of care.

The system described is comprehensive, principle-based and evidence-informed, and is intended to support family caregivers so that they can provide the best possible care to adults living with TBI while maintaining their own well-being.

These guidelines will ensure that the negative challenges experienced by family caregivers from the rural backgrounds are attended to and some recommendations for addressing them are made.

Although the recommendations are applicable to the family caregivers of anyone with traumatic brain injury, the focus is on all those who care for adult patients with a chronic condition at home in the rural settings.

This document acknowledges the potentially significant distress that family caregivers experience when the needs of the person they care for are not adequately addressed. The focus, however, remains on the support required by the family caregivers themselves.

- Well-supported family caregivers can play a facilitative role in the recovery journey of their ill relative and in the improvement of their quality of life.
- Adequate support can mitigate the stressors often associated with caregiving.

- The absence of such supports, on the other hand, can lead to negative effects for family caregivers that jeopardize both their capacity to provide care and their own health and well-being.
- The unpaid care and support provided by family caregivers makes a major contribution to the health and social service system, which would be very costly to replace with paid formal services.

When asked about what would they most want the healthcare professionals do for them as a way of supporting them in their caregiving roles, the family caregivers who participated in the semi structured interviews said that they needed:

- To have their relationships and caregiving role recognized by healthcare professionals and service providers and to be meaningfully integrated in care plans and management of their patients.
- To have access to information, skills, support groups and services from knowledgeable health service providers to enable them to effectively provide care to the person living with traumatic brain injury.
- To receive support and services for the family and its individual members to sustain their health and emotional well-being.

  Other needs identified by participants and noted in the research literature are need for recognition, validation and support from other family members, the community, employers, government and healthcare providers in general.
- Participants also identified the need for help with daily caregiving activities, along with emotional and financial support.

  Some complained that their family members would not assist them with caregiving and were as such pleading for respite care.
- To know that the person they care for is receiving adequate care and services, and is able to achieve a reasonable quality of life. They were concerned about what would happen to their patients in case the family caregivers die, who would attend to them.

6.3.1 Guideline 1: Facilitation of perception of being an overcomer

Purpose: To promote a therapeutic and reassuring environment to activate a relationship of support for family caregivers

In order to formulate this guideline, the researcher summarized the findings related to the challenges associated with not being in control of the sudden situation of TBI patients by family caregivers. See Box 6.1 for a summary of findings that were used by the researcher to deduce the guidelines in this section.

Box 6.1 Summary of conclusion statements for challenges associated with understanding the behaviour of professional health providers of TBI patients

- Their concerns were not answered adequately by the healthcare professionals.
- The intensive care environment was very frightening and not conducive for families.
- No one was prepared to answer their questions – always being told to wait and see.
- Did not know what questions to ask related to the condition of the patient.

Therefore, based on the summary provided in Box 6.1 above, the researcher formulated activities as detailed below.

Recommended activities and procedures for the implementation of the guideline:

Therapy should include the following:

- Healthcare professionals should be truthful in explaining the extent of the problems the patient may have and offer direct advice.
- Provision of health education regarding the environment and procedures in the high care units like the ICU. Families should be conversant with the environments of the intensive care units so that they are not shocked when they enter the units.
- Presentation of information empathetically using simple language and when possible, written information should be presented with visual aids that families can use for future reference.

- Reassurance of family caregivers and explanation of myths and misconceptions about the condition like when they say TBI is caused by witchcraft or has been called by the ancestors, stressing that it is important to focus on the positives.
- Facilitate the internalization of personal rights by informing caregivers and families of their rights and the government's policy on patients' rights - Batho Pele principles.
- Encourage the family caregivers to express their feelings of guilt, anger and sadness and any other feelings associated with the change in lifestyle, without having qualms about that, ensure debriefing sessions are available.
- Provide advice on the causes, nature of problems that the patient may be undergoing so that their tolerance is boosted.
- Truthful advice on the questions asked and those perceived to be stressing the family caregivers.

6.3.2 Guideline 2: Active participation in decision making about the patients

Rationale: Active participation is the major contributing factor in the provision of quality care for patient and promotion of health for caregivers

Box 6.2 Summary of conclusion statements for challenges associated with inability to actively participate in the care of their patients

The study found that the participants:

- Had no prior preparation for the situation they found themselves in and some tried strategies and defense mechanisms to gain mastery of the situation – *leaving the patient and go cry away from him.*
- Use of denial, spirituality and hope whilst some used positive refocusing to minimize the significance of the condition – *take it one at a time*.
- Sadness by witnessing their patients and not being able to assist them in their incurable disease.
- Adoption of a problem focused attitude in that they executed some behaviours to modify their relationship with the environment which is the source of stress by either modifying the environment itself or modifying their behaviour towards such environment (Padden, Connors & Agazio 2011:252) - *telling the people concerned that the person is having a problem or just ignore the behaviour.*

This can be remedied by:

- During the in-patient period and continuing post discharge there is a need for psychological counselling and support to family caregivers to assist in coping with the multiple losses experienced and to facilitate the normal adaptation process.
- During rehabilitation healthcare practitioners should actively involve the family caregivers in educational sessions so as to enhance their beliefs about their abilities to cope in challenging situations of life. This enhancement is achieved through building models of care and providing appropriate counselling services.
- Healthcare practitioners should form collegial bonds with family caregivers so as to ensure growth of support connections.
- The rehabilitation team should also occasionally provide family caregivers with counselling and debriefing sessions as a means of support and team building (Abasaibong et al 2011:495; Khangèthe 2009:115).
- Mobilization and gaining access to support resources and information to enable them to gain access to the relevant knowledge and skills and be referred to psychological, social, religious and cultural resources to enable them to be independent and gain self-reliance in the care, treatment and rehabilitation of their patients (James 2006:79).
- Advocating for the development of health financing plans that provide payment for a range of self-care education for all ages.
- Development of user friendly and culture sensitive educational materials and support programs to create awareness in the rural communities about the condition TBI and what expectations of the caregivers should be.
- Awareness programs should be arranged to foster the spirit of working together so that every member in the family or community feels ownership and responsibility in being involved in the care of such individuals
- The rehabilitation team and community healthcare providers should provide TBI expertise to family caregivers. Further, it is suggested that the rehabilitation counsellors should adopt a systemic ecological model in their work which would focus counsellors towards the identification of environmental as well as coping

- resources which are crucial to adjustment, rather than employing a psycho-medical paradigm which has been pervasive in the history of rehabilitation.
- It is necessary for healthcare workers to maintain frequent contact with TBI sufferers and their family caregivers so that events that occurred during the last contact could be reviewed and assessed and this means that family caregivers get an opportunity to vent their challenges.

This then means that healthcare practitioners have to identify the stages that the caregiver is in, in order to intervene appropriately. Denial is seen as an attempt to retain the meaning, control and identity of the pre-injury state. It has been acknowledged from existing evidence that in order to survive any chronic disease, remaining hopeful is one of the crucial aspects that must be maintained and sustained by caregivers (Grónlie 2011:167; Ródlack 2009:427). Bond et al (2003) state that information should be provided by a designated healthcare provider to reduce stress and assure message consistency.

6.3.3 Guideline 3: Creation of awareness about the available resources to help address care issues of TBI patients

Outcome: Appropriate resources, human and material are available for the support of patients and family caregivers.

Rationale: The availability of resources is the major contributing factor in improving the quality of care and support of family caregivers.

Box 6.3 Summary of conclusion statements for challenges associated with caregiving of TBI patients by the family caregivers

- He is very aggressive and is short tempered, he breaks things.
- He does not want to be in a rowdy place.
- We no longer invite people in our home because we are afraid he may start his tempers.
- We have to wake people in the middle of the night to transport him to hospital because there is no ambulance.
- We do not go out with children anymore because of financial constraints.
- I have to do roles that were initially done by my partner.

- I am away from work most of the time having to accompany him to the lawyers and the hospital.
- We do not see any healthcare professionals here
- I have to accompany her to hospital she gets lost easily yet she grew up here
- He is having anti-social behaviour, he will go and sit in secluded place until we leave

Recommended activities and procedures for the implementation of the guideline:

Therapy should include:

- Provide a variety of respite options in the community that can be tailored to family caregivers' preferences.
- Increase financial awareness about availability of financial support so as to alleviate financial difficulties.
- Improvement of transport services for TBI patients which are user friendly for such patients.
- Social workers to promote access to social services like social grant.
- Community health nurses should lead in assisting family caregivers and their patients to cope with stress of long-term care.
- Development of user friendly and culture sensitive educational materials and programs to create awareness in the rural communities about the condition TBI and what expectations of them should be - awareness programs should foster the spirit of UBUNTU.
- Psychological health services should be provided for counselling and family caregivers should be encouraged to use such services.
- Nursing strategy should be geared in the improvement of provision of healthcare services the Eastern Cape.
- Use of protocols for managing TBI caregivers and patients.

6.3.4 Guideline 4: Improve professional healthcare providers' involvement and availability in the care of TBI patients post discharge from hospital rehabilitation

Outcome: Continuous provision of assistance to communities taking into account that they have cognitive difficulties in health issues – to enhance understanding of the condition.

Box 6.4 Summary of conclusion statements for challenges associated with follow-up care of TBI patients and the family caregivers by healthcare providers

- Languages used are too technical and not understandable.
- You are not allowed to read the patients notes.
- When I was with her for the first time in my car I realized that now this is it. It is going to be me and her.
- You are just left in the deep end; I did not know what to do with the bandages.
- Not all healthcare providers come to make visits, only nurses do come but their coming is useless because they do not have medications.
- We were promised availability of mobile clinics but we saw them only once.
- Conditions of the roads are not good they are inaccessible.
- Use of social grants for transportation and medications.
- Do not know whom to communicate with - the relevant professionals for their social problems. Some were still waiting over a year as they were being assessed for theireligibility to destitute policy.

In this study nurses were found to be scarce when it came to home visits. Follow up of patients by healthcare professionals was not as frequent as expected. Community health nurses very rarely went on home visits. Those who were occasionally seen were of lower levels in the profession like staff nurses and assistant nurses without medical equipment to assist patients and family caregivers. They were less skilled to give guidance on chronic conditions like TBI.

Through follow-ups, the professional nurses can assess how the family caregivers are coping with caregiving activities. There is also a need to assess whether change has taken place in the home environment like adjustments to the homes in order to ensure positive environments for the patients.

This is a disturbing situation as the community health nurses are employed to work in the communities. Nurses exist in the community to provide the necessary support to patients and their families. With the chronicity in disease profiles in South Africa, resources have become scarce including professional healthcare workers.

Recommended activities and procedures for the implementation of the guideline:

- Capacity building for family caregivers should be prioritized so as to alleviate their stress and equip them with skills for positive coping which the study showed to be lacking. Psychotherapy of family caregivers should be done occasionally.
- Communities and families at large should be educated on the important role played by the family caregivers and the challenges they face so that they can be appropriately assisted.
- The communities should be further assisted by both the government and the non-governmental organizations (NGO) in the establishment of social support networks that will target family caregivers specifically of TBI patients.
- The time to measure progress towards goal attainment must be mutually agreed upon by all parties, including methods used.
- There should also be a mutually agreed upon frequency of follow-up visits.
- There should be communication on how best to access financial resources.
- Introduction of technological innovations such as telehealth, telemedicine, teleconferencing, internet and WhatsApp messaging groups are better used for other chronic disease monitoring (Bensink, Hailey & Wooton 2006:8); Buckley, Tran & Pradoni 2004:9).
- Improvement of social services network to facilitate family caregivers support

6.3.5 Guideline 5: Improvement of inaccessible roads, public transport and social support facilities

Outcome: Accessibility of roads and social support would boost the morale of caregivers and improve their quality of life.

Box 6.5 Summary of conclusion statements for challenges associated with inaccessible roads, transport and social services

- Have difficulty transporting patients for rehabilitation services because of lack of reliable transport services.
- Dependency on social grant, lack of funds to transport patients and for seeking private healthcare and buy medication.
- Long waiting lists and queues in the healthcare centres.

- Loss of financial income.
- Long distances from healthcare facilities.
- Would not be able to provide basic care like bathing of an opposite sex.

This constraint could be linked to the political legacy of the apartheid system where people were displaced to the outskirts without guarantees of safe and reliable public transport systems. These socio-political changes still have an effect on some populations even at this day. One old lady participant related that they make use of wheel barrows to transport sick people to the clinic and or ambulances which could not reach their homes because of bad condition of their roads.

Recommended activities and procedures for the implementation of the guideline:

- There should be bridging of barriers due to geographical barriers by having stipulated days where healthcare providers and stakeholders from different departments of the province could be transported to the communities even if it through the use of helicopters so that they are aware of the dire situations that these people come from.
- Professional nurses to act as advocates for family caregivers in terms of communicating with other healthcare professionals so that there is fluent referral and availability of services.
- Referral to relevant service providers from within the community to promote accessibility of health services. In other words, they should be able to liaise with social workers and Department of Home affairs personnel for those in need of social grants.
- Government structures tasked with welfare services should conduct workshops in communities to sensitize families about the support services available to them so as to alleviate the burdens involved in caring.
- Provision of respite caregivers to assist family caregivers - the healthcare providers should expand home based care programs to find ways to assist households.
- There should be special days or special services in clinics for patients with TBI so that they get immediate attention and not spend the whole day in the facility.

- Provision of increased representation of community stakeholders in health committees so that they can voice their concerns regarding the allocation of resources at decision-making levels.
- Consistent in-service training for family caregivers on how to access resources would relieve pressure on caring. In order for family caregivers to have continuous control over their situation they should be seen as partners in the health system.
- Creation of awareness about available resources to help address the care issues of TBI family caregivers'
- Income generating activities should be fully supported in order to make up for the deficit caused by caring for TBI patients.

6.4 EVALUATION OF THE GUIDELINES

The guidelines formulated for support of family caregiver of patients suffering from TBI have been given to experts in the field of critical care nursing and general nursing science for evaluation of clarity, simplicity and adequacy for implementation. The researcher also provided the guidelines to the nurses working in general hospital wards and clinics in order to obtain their feedback and suggestions. The Eastern Cape Department of Health coordinators and district health departments both participated in giving comments and in building the guidelines to improve the care rendered to TBI patients within rural communities of the Eastern Cape. Therefore, the guidelines were evaluated for clarity, simplicity and operational adequacy. All those who participated in this endeavour found the guidelines well developed to render support to caregivers of patients with TBI.

6.5 CONCLUSION

In this chapter, the guidelines were formulated to support the family caregivers of patients with TBI in the Eastern Cape Province. The next chapter deals with the conclusions and limitations of the study and makes the recommendations for practice and further research. The Batho Pele principles should be considered when attending to such caregivers. This can be achieved by (1) encouraging positive communication between family caregivers and health professionals, (2) promotion of self-assessment and active participation of family caregivers in the decision making about their health and those of their patients and, (3) monitoring of development of TBI support group hotline for correspondence, information and support as they pursue the actualization of wholeness.

The following chapter is the last chapter dealing with summary, conclusion, recommendations and limitations of the study.

CHAPTER 7

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

7.1 INTRODUCTION

This chapter is aimed at summarizing the study, identifying strengths and limitations of the study and making recommendations to improve support for family caregivers by the healthcare professionals and for further research studies. The study focused on the family system with an aim to understand the family caregivers' experiences of TBI.

7.2 SUMMARY OF THE STUDY

An extensive literature review was conducted to examine and establish theories that explain the experiences of family caregivers in similar situations that relate to the topic of the research study. A family systems theory was identified and chosen to form the conceptual framework for the study, as it was mentioned in the previous chapters, that it sees different levels of groupings of the social contexts as systems where the functioning of a whole is dependent on the social interaction of its parts. It is against this background that the family is seen as a system whose functions, externally and internally, are interdependent on each other.

The overall aim of the research study was to develop a model for the facilitation of support for family caregivers of TBI patients and through the research done incorporate the knowledge gained in the nursing practice. This was accomplished by doing a qualitative, descriptive, contextual and exploratory research using semi-structured interviews to get information from the participants who were family caregivers of patients with TBI.

The family caregivers who made the sample were primarily Xhosa speaking participants from the remote rural O R Tambo area of the Eastern Cape. The ages of the participants ranged from 23 years to 68 years of age. One of the most salient findings that emerged from this study is that almost the entire research population consisted of women, with only one man being a caregiver.

A conclusion drawn on this fact is that caregiving seems to attract more women than men – a view that Bharat and Mahendra (2007:112) mentions in their study. Motor vehicle accidents were the main cause of injuries followed by trauma. Visiting the family caregivers at their homes not only enabled the researcher to observe domestic arrangements that added depth to her understanding of the phenomenon under study, but it also created intimacy with the participants so that they could tell very interesting stories and could relate to the stigmas associated with TBI. The research question was:

Tell me, what are your experiences of giving care to a person who has traumatic brain injury?

This question was formulated on the basis of personal experiences, professional encounters and a gap identified in the local research literature. The literature search revealed a lot of information on research publications regarding informal caregiving but these were in developed countries. In developing countries, where there is an increased need of informal caregivers, limited research has been done to explore the experiences, needs and concerns of the caregivers.

Participants displayed willingness to talk which was accompanied by mixed feelings/emotions such as a sense of hope and hopelessness, courage and discouragement to continue as caregivers. One could feel in them a sense of wanting to overcome the obstacle, - if only - they could get information and social support – was their cry. The sudden and immediate nature of the disruption that occurred in their families due to the trauma was reflected in the way the participants engaged in denial of the reality of the situation.

The environmental variables which included geographical barriers, as the roads are in appalling state, unavailability of transportation facilities were peculiar to this rural population setting. Participants' period of being family caregivers differed and as a result they answered differently given their distance of time from the TBI event.

The results of this study support the notion that TBI is a significant health problem that affects not only the individual but the whole family for a long time. It is also clear from the results that the impact of TBI on the family caregivers was modified by unique variables such as coping mechanisms, family dynamics and relationships before the incidence. Categories that emerged from data analysis were used to describe the phenomenon being investigated.

The findings that emerged were discussed using the three (3) themes and subcategories that emerged from the data which were:

- Experiences related to caring for a traumatic brain injury patient, with subcategories of grieving and trauma, feelings of despair and denial, lack of information from healthcare professionals and effects on the family.
- Challenges with long-term caring, subcategories being fear and uncertainty.
- The needs of caregivers of TBI relative with the subcategory of coping mechanisms.

7.3 RESEARCH FINDINGS

The findings of this study concur with a study by Oddi et al (2006:90) that a family goes through an immense pressure after a family member has sustained a traumatic brain injury. The suddenness of the injury disrupts the family structure and affects the family financially, psychologically, emotionally and otherwise. Other findings included that:

- The needed health services were not available and accessible to TBI patients and their family caregivers.
- The interaction between the professional healthcare providers and family caregivers was perceived as not yielding very satisfactory results, as the family caregivers are usually not adequately prepared for their role because of the suddenness of the condition of TBI.
- Professional healthcare providers were not supportive to families as they would be reluctant to answer and attend to their questions and anxieties and as such family caregivers were not satisfied with the quality of healthcare provided by health professionals especially those within their communities.

The researcher then concluded that although the family caregivers are the key players in the provision of care outside the hospital setting they do not get the recognition and support they deserve.

7.4 STRENGTH OF THE STUDY

The strength of the study was the data collection method which included face to face semi-structured interviews. Face-to-face interview has a potential to increase the richness of the data and further understand the subjective experiences of the participants.

Strength was also in studying an emerging issue of traumatic brain injury which had not been regarded as a chronic condition that needs exploration and discussion in order to better address it. The study was the first study for TBI family caregivers to be done from a rural setting. This made the researcher to identify other issues that she was oblivious to which highlight the way rural communities are disadvantaged and ostracized.

7.5 LIMITATION OF THE STUDY

Burns and Grove (2008:39) state that limitations are restrictions or problems in a study that may decrease the transferability of the findings. The researcher had confidence that the participants in this study were experienced in being family caregivers and were thus able to provide rich information and had agreed to give out as much information as possible.

However, the study had the following limitations:

- The findings could be inclusive, if the TBI patients cared for in this context were involved.
- The study was limited to family caregivers who were from OR Tambo District Municipality only and could not be generalized to other regions in the Eastern Cape Province and outside.
- The experiences and challenges of other caregivers from other regions might differ from those that were studied. It was impossible for the researcher to carry out a larger study owing to time constraints and the nature of research as it was qualitative. Qualitative research does not need a large sample.
- The findings of the study could only be applicable to caregivers who were sampled.

7.6 BIAS OF THE STUDY

The researcher identified some biases in the study

- Racial bias - All nine participants were of African origin. The study lacks cross cultural research. It was impossible to have other cultures because the study was conducted in a Black rural setting.
- Gender bias- All nine participants were females. This could not be avoided as mostly it is only females who take the responsibility and the initiative when there is a need for caring.

7.7 RECOMMENDATIONS

The study did not cover the whole of O.R Tambo district municipality but used few participants from few locations in the rural settings. However, the findings can serve to increase the awareness of policy makers to the needs of family caregivers of all chronically ill patients because they all should have different challenges.

Based on the findings possible remedies for some of the challenges experienced by family caregivers were identified and these were seen as that they could complement the already existing support services.

The researcher, therefore, recommends the following:

- The practice of continuously including family caregivers in the programs that involve them. Many family caregivers complained of lack of information and dissatisfaction with the practice of being excluded.
- Communities and families at large should be educated by healthcare professionals on the importance of the role of family caregivers and the challenges they face so that they can be supported appropriately.
- Community support networks that will target family caregivers of TBI patients should be established.
- Capacity building for family caregivers to cope with TBI issues should be prioritized so as to alleviate their stress and equip them with skills for positive coping which the study showed is still lacking. Counselling services should be involved
- The findings also revealed that family caregivers had no clue of the available services for them. The researcher, therefore, recommends that the government structures tasked with the welfare of family caregivers should continuously conduct workshops in communities to sensitize their members especially caregivers about the support services available to them to alleviate burdens of involved in caring.

- Churches and community structures should provide basis for emotional and psychological support for family caregivers as spirituality and religious services often play an essential role in health and healing, offering hope in the midst of life’s challenges.
- The study has revealed that most materials and workshops on awareness programs are conducted in foreign languages thus excluding those who do not know the language.
- Government structures relevant for social development and non-governmental organizations should establish support groups to assist patient’s family caregivers and healthcare professionals in the care of TBI by providing respite care services.
- Family caregivers should be empowered continuously with information on TBI, strategies for preventive measures, homecare support and the empowerment programs should be culturally appropriate appealing to the level of maturity of all family caregivers.
- The family systems model promotes family therapy rather than treating a patient as an individual, therefore, family involvement and sharing in the caregiving of a patient with TBI would lessen the burden in the caregivers
- Family caregivers’ income-generating activities should be fully supported by NGOs and the government in order to make up for the deficit caused by caring for a TBI relative.
- The government should formalize the system followed for family caregivers of TBI patients and support them financially in their caring endeavours, as the study has revealed that they are financially crippled by the expenses of caregiving.
- The government should include family caregiving for TBI patients as an integral part of PHC program planning, as this would ensure that all members of the family were involved. Family caregivers would receive family support and would not be left to fend for themselves in their caregiving role.

7.8 PERSONAL EXPERIENCE DURING THE STUDY/PERSONAL REFLECTION

The researcher kept a reflective journal to record her experiences and personal feelings on remarks. The information that was jotted down during these instances helped to remind her on the aim of the study irrespective of the feelings and experiences she encountered. Sometimes it would be difficult to blot them out of her mind especially the pathetic experiences that she would encounter when she was visiting the homes of the participants.

7.9 RECOMMENDATIONS FOR FURTHER STUDIES

In this research study there were voids in literature regarding family caregivers as there was little or no South African literature on family caregivers from rural communities.

Based on the findings and the researcher's experience in this field, it is recommended that attention be drawn to research regarding caregivers.

As a result of this study, the possibilities for future research are:

- To identify and describe the experiences of survivors of traumatic brain injury due to trauma and accidents.
- The development of a program for the support of family caregivers.

7.10 CONCLUSION

The study found a lack of psychological intervention during the in-patient rehabilitation period and poor discharge planning in terms of involving the families and ensuring home adaptations, educating them on the skills to be able to cope with the attitudes of the community especially those that are influenced by lack of knowledge. Community support was lacking and participants' lives were compromised by poor infrastructure and a lack of transportation.

More sensitivity to the care needs of everyone, not only people with extreme care need due to illness and disability, will provide a foundation upon which long-term care and support can rest. There is a need for everybody to acknowledge the interdependence of one to another as said in the African idiom "umntu ngumntu ngabantu." If that principle is entrenched from the beginning provision of caregiving will be less of a shock when such a time comes to anyone.

Family caregiving can also be strengthened by the complete support of healthcare providers forming interrelationships with all the stakeholders of the local municipalities so as to address all the needs of the rural family caregivers. Family therapy principles should be included in all the training programs aiming at stabilizing the whole family system. All TBI patients should be registered as chronically ill patients and their family caregivers so that they can qualify for social grant services.

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ANNEXURES

ANNEXURE 1

ETHICAL CLEARANCE CERTIFICATE

UNISA university of south africa

UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE

HSHDC/307/2014

Date: 12 February 2014 Student No: 583-237-3

Project Title: A model of support for family caregivers of traumatic brain injury survivors following discharge from hospital rehabilitation in the OR Tambo District of the Eastern Cape in South Africa.

Researcher: Nomawethu Constance Mjekula

Degree: D Litt et Phil Code: DPCHS04

Supervisor: Prof MM Moleki
Qualification: D Litt et Phil
Joint Supervisor: Prof M Matlakala

DECISION OF COMMITTEE

Approved ☑ **Conditionally Approved** ☐

LRoets

Prof L Roets
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE

ANNEXURE 2

REQUEST FOR PERMISSION TO CONDUCT A STUDY

Dear Counsellor

My name is Nomawethu Constance Mjekula, a lecturer in the service of Nursing Department of Faculty of Health at Walter Sisulu University. I am a part-time doctoral candidate at the University of South Africa. In the fulfilment of the requirements for my doctoral qualification, I have to undertake a research project. I have consequently decided to focus on the research topic: **Model of support for family caregivers of Traumatic Brain Injury patients post discharge from hospital rehabilitation in the O R Tambo District Municipality, Eastern Cape.**

This project originated as a result of an identified gap in the knowledge and practice in the area of caregiving to TBI patients. The primary purpose of the study is to understand the experiences and the challenges of the family caregivers in relation to caring for TBI patients and to develop a model of support in order for them to overcome their challenges.

In view of the fact that the family caregivers are well informed of the topic, I hereby approach you with the request of your permission to conduct a study in your ward. The data gathered from this study will provide an insight into the experiences and challenges faced by family caregivers of TBI patients, their support preferences from healthcare professionals and further inform decision makers when they design and develop policies and programs. The study will take a form of some interviews which will last for about forty-five (45) minutes to an hour with family caregivers in their homes.

For ethical responsibility, I am obligated to treat the participants with respect. I will ensure that they are protected from any harm, deliberate and otherwise. The participants shall not be forced to be part of the study and those willing to participate will be informed that they will be allowed to withdraw from the study anytime they so feel. They shall be informed that all the data given to me shall be kept in confidentiality. Participants will sign informed consent forms after clearly explaining the study to them.

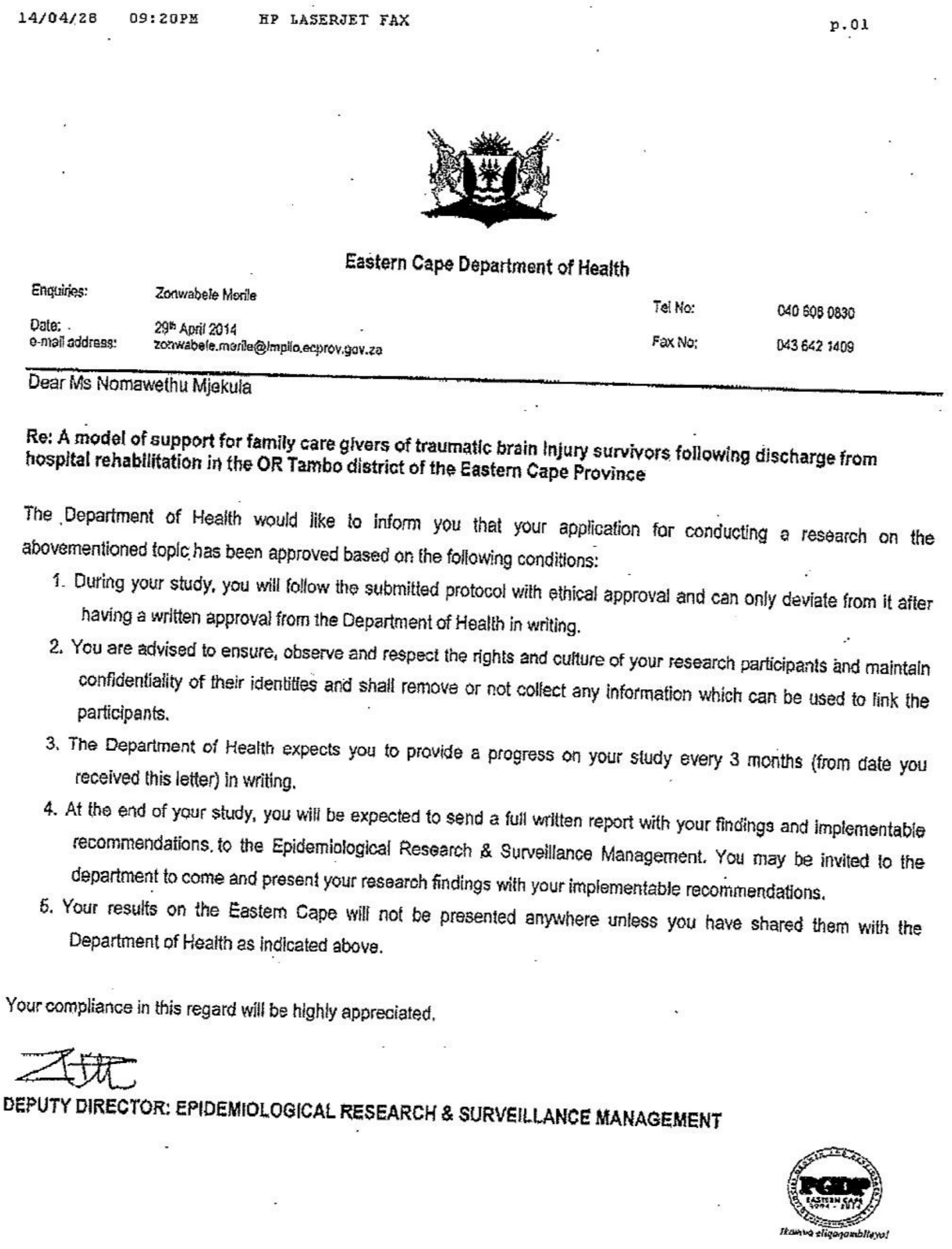
All the ethical principles that I, as a researcher commit to, will be clearly stated in the consent form.

It is, therefore, my conviction that being granted permission by you to conduct this study will contribute towards provision of knowledge for support of family caregivers of TBI.
Thanking you for your consideration.

NC Mjekula……
Principal Researcher

ANNEXURE 3

PERMISSION GRANTED TO DO THE STUDY



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Eastern Cape Department of Health

Enquiries: Zonwabele Merile
Date: 29th April 2014
e-mail address: zonwabele.merile@impilo.ecprov.gov.za
Tel No: 040 608 0830
Fax No: 043 642 1409

Dear Ms Nomawethu Mjekula

Re: A model of support for family care givers of traumatic brain injury survivors following discharge from hospital rehabilitation in the OR Tambo district of the Eastern Cape Province

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT

PGDP
EASTERN CAPE
1994 - 2014
Ikamva eliqaqambileyo!

ANNEXURE 4

INFORMED CONSENT FORM

TITLE: A MODEL OF SUPPORT FOR FAMILY CAREGIVERS OF TRAUMATIC BRAIN INJURY PATIENTS FOLLOWING DISCHARGE FROM HOSPITAL REHABILITATION IN THE O. R. TAMBO DISTRICT MUNICIPALITY OF THE EASTERN CAPE, SOUTH AFRICA

PURPOSE: You are being asked to participate in a study which is aimed at investigating experiences of family caregivers of traumatic brain injury patients. This form is designed to provide you with the information about this study and to answer some of your questions.

PROCEDURE: If you agree to participate in this study you will be interviewed by the researcher at a time and place that will be convenient to you. The interview session will take forty-five minutes to an hour of your time.

RISKS: There are no known associated risks with participation in this study. You are not required to reveal any information that makes you uncomfortable. You may refuse to answer any question you do not wish to answer.

BENEFITS: There are no benefits expected for your participation in the study. Although the information that we obtain may not benefit you directly, I believe the results of the study may contribute to a better understanding of the impact of a traumatic brain injury to family caregivers and the families at large.

CONFIDENTIALITY: All information that refers to you or that can be identified with you will be strictly confidential to the extent permitted by law. Other than this form all the data will be identifiable only by a code number. Your performance will not be revealed to anyone without your expressed permission.

PARTICIPATION IS VOLUNTARY: Your participation in this study is voluntary. If you wish, you may decline to participate, simply by informing the researcher. Your decision not to participate or to participate and later withdraw from the study, will not in any way result in a penalty to you.

COSTS: Participation in this study should not involve any additional costs to you. The researcher will go and meet you at a place that will be convenient to you.

You will be provided with the signed copy of your signed informed consent form.

I have read and understand the above

I agree to participate

I do not agree to participate

Signature of the participant ------------------- Date---------------------

Signature of the researcher ----------------- Date---------------------

ANNEXURE 5

INTERVIEW SCHEDULE

The researcher shall first thank the participant for agreeing to participate in the research study. Before starting the interview there shall be a session to review the informed consent in order to address any queries that the participant may be having

The researcher shall ask the following grand question and will utilise the interview schedule to guide her on what data she would want to have.

What are your experiences in caring for a person who is suffering from traumatic injury?

The following are the questions that will be used as an interview schedule:

- Tell me about yourself and your family. What is your relationship to the patient?
- What is your understanding of a traumatic brain injury?
- What was your experience when the patient was admitted in hospital regarding the treatment and communication between you and health care workers?
- How was your relationship with the patient before the injury and how has it been affected now? How does it feel to have a member that is suffering from traumatic brain injury? What impact does this injury have to you and in the family at large?
- How was the personality of the patient before and after injury- what personality changes do you experience now? What are the new behaviours that you observe as you are caring for the patient?
- How has this injury impacted your relations with the other members of the family?
- When reflecting on this journey of caregiving what are the things that are surprising to you as a caregiver? What is the most difficult behaviour you have to confront whilst providing care to your patient?

- What is the attitude and treatment that you get from the family/community regarding the patient and your caring roles? What type of support do you receive from people?
- What are your immediate needs that will cater for the whole family and the patient?
- How would you like to be assisted with as you continue to provide care to a TBI sufferer?