

**Traumatic brain injury (TBI) patients' post-acute
rehabilitation:
the experience of family members**

Mini-dissertation

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Master of Social Work in Health Care

MSW (Health Care)

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Karen Thiant

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Faculty of Humanities

University of Pretoria

Supervisor: Dr. C.L. Carbonatto

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**UNIVERSITY OF PRETORIA
FACULTY OF HUMANITIES
RESEARCH PROPOSAL & ETHICS COMMITTEE**

DECLARATION

Full name : Karen Thiar

Student Number : 9908281-2

Degree/Qualification: MSW (Health Care)

Title of thesis/dissertation: Traumatic brain injury (TBI) patients' post-acute rehabilitation: the experience of family members

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To my husband, Hennie for his loyal support, encouragement and love through my completion of this degree.

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ABSTRACT

Title: Traumatic brain injury (TBI) patients' post-acute rehabilitation: the experience of family members

Candidate name: Karen Thiar

Department: Social Work and Criminology

Degree: MSW (Health Care)

Supervisor: Dr. C. L. Carbonatto

A traumatic brain injury (TBI) is what its name suggests: an extremely traumatic event that affects the most supremely powerful but fragile organ that controls all our bodily functions and holds the essence that makes individuals unique. Some patients with a traumatic brain injury will recover without realising what the effect could have been and others will be left with effects that will last throughout their lives. "Many sufferers will remain severely incapacitated and a lamentably large number will become part of the statistics on the mortality after TBI" (Burns, 2008a:76). The impairments that an individual faces after a TBI will be dealt with in an acute rehabilitation setting.

Significant emotions are experienced by patients with a traumatic brain injury. The researcher believes that this emotional reaction is also experienced by the family members. The event may be even more devastating to the family members, because of the impaired cognitive functions of the injured person. Ross and Deverell (2004:36) state that when individuals are diagnosed with disabling conditions, they experience strong emotional reactions. "Feelings of grief, anxiety, inadequacy, anger, guilt, vulnerability and confusion are some of the more common emotions that clients and their families experience when they encounter a disability in themselves or a family member" (Ross and Deverell, 2004:41).

After a traumatic brain injury the patient is usually admitted to an intensive care unit (ICU). Once medically stable and able to participate in an active rehabilitation programme, provided this is authorised by the patient's medical aid, the patient is transferred to a rehabilitation unit. While in ICU, the outcome is very uncertain and the the family often receives very limited support. Patients are often in a coma and

unable to communicate. In working with TBI patients, the researcher found that family members receive very limited support, education on the condition and feedback on the patient's medical state from team members, and therefore become very anxious when the patient is eventually transferred to a rehabilitation unit. In this study, the researcher focused on the family's experience from the time of the patient's admission into ICU until discharge from rehabilitation. During the rehabilitation process, family members are encouraged to support their family member in the rehabilitation unit. This is often very difficult for them, as it entails being confronted with reality and the often devastating impact of the injury.

The focus of this study is on the experiences of family members while the patient with a TBI is in hospital and in the rehabilitation unit and the challenges they face. The researcher strove to understand the experiences of family members of patients with TBI, from ICU through until discharge from acute rehabilitation. The goal was to explore the experiences of adult family members of the traumatic brain-injured person in post-acute rehabilitation. The research question was: What were the experiences of adult family members of the person with a traumatic brain injury (TBI) during post-acute rehabilitation?

A qualitative approach was used in this study, with a collective case study research design. The population for this study was all the family members of patients who underwent rehabilitation as a result of traumatic brain injury in the Life Eugene Marais Hospital, Pretoria, Gauteng. In this study purposive sampling was used to choose participants who were family members of TBI patients. The criteria for sampling of family members as participants were as follows. The patient

- had suffered a traumatic brain injury;
- had undergone acute rehabilitation at Life Eugene Marais Hospital for the last four years;
- had completed rehabilitation, in other words had to be post discharge;
- lived in the province of Gauteng; and
- was able to speak and understand English or Afrikaans, irrespective of gender, race, religion, culture or age.

Eight participants who were family members of eight TBI patients were chosen for this study.

Semi-structured individual interviews were conducted with participants. Interviews were voice recorded with the permission of the participants and were transcribed by the researcher. The data were analysed by the researcher and the themes and sub-themes generated from the data. The research findings were presented by providing a profile of the research participants and then presenting the themes and sub-themes, including literature control and verbatim quotes from the transcriptions. The themes included the following: Theme One – Understanding of TBI; Theme Two – Period of hospitalisation; Theme Three – Family members’ emotional experience of TBI; Theme Four – Period of rehabilitation; Theme Five – Period post discharge; Theme Six – Support systems; Theme Seven – Effects of TBI and Theme Eight – Future.

The conclusions of this study are that traumatic brain injury (TBI) is experienced as severe trauma by family members, who struggle to cope not only initially but especially once the person is discharged and has to be cared for at home. In the long term this experience leads to changes in the family regarding structure, roles, functioning, relationships, communication, finances and social life.

Recommendations in this study can be used by the multidisciplinary team to better understand the needs and experiences of the family members of TBI patients and by social workers to improve their intervention and support to these families.

LIST OF KEY TERMS

REHABILITATION OF PEOPLE WITH DISABILITIES

TRAUMATIC BRAIN INJURY

FAMILY MEMBERS

COGNITION

ATTENTION

EXECUTIVE FUNCTIONS

PERSEVERATION

CAREGIVERS

REHABILITATION SOCIAL WORK

MULTI DISCIPLINARY TEAM

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CHAPTER 1

GENERAL INTRODUCTION

1.1 Introduction

When we successfully treat a patient... we experience a burst of joy because we have helped a suffering person who is happy to have known us. But we also feel a secret joy; because we have come to know him, and in knowing him we know more of ourselves (Sylvano Arieti, in Brewer, 1995:i)

A traumatic brain injury (TBI) is what its name suggests: an extremely traumatic event that affects the most supremely powerful but fragile organ that controls all our bodily functions and holds the essence that makes individuals unique. Some patients with a traumatic brain injury will recover without realising what the effect could have been and others will be left with effects that will last throughout their lives. “Many sufferers will remain severely incapacitated and a lamentably large number will become part of the statistics on the mortality after TBI” (Burns, 2008a:76). The impairments that an individual faces after a TBI will be dealt with in an acute rehabilitation setting.

Rehabilitation does not revolve around a sick patient who is waiting to be cured. Chronic dysfunctions that are often incurable and irreversible are treated but often leave residual disabilities that may continue throughout a person’s life. Individuals and their families are left to cope with uncertain demands for the rest of their lives. Disabled persons have a restricted ability to perform activities in a way that is perceived to be normal and rehabilitation strives to improve quality of life by increasing independence, participation in life events and general life satisfaction, that will help the patient to live as satisfactory and fulfilling a life as possible. Therapy in rehabilitation attempts to reduce the handicap by restoring certain skills and capabilities through re-training and environmental adaptation. This includes working towards restoring skills to a level that compares with pre-morbid functioning and recognising and accepting skills that the disabled person is unable to regain. Rehabilitation further includes individualised choices and decisions depending on the degree of disability, the family and social environment and preferred lifestyle. The onset of severe disability can have a great effect on existing personal relationships and the forming of new relationships. Rehabilitation is therefore focused on compensatory strategies that allow the disabled

person to function at the highest possible functional and social independence level (compare Haas, 1998:35; Ingram & Grundy, 2002:57; Wallace, Evan, Arnold & Hux, 2007:1371; Winterhalter, 2001:213.)

The researcher worked at a Life Rehabilitation Unit from 1 July 2006 until 30 April 2011. During this period she dealt with many TBI patients and their families. It has been stated that there is little documentation on the daily experiences of patients during rehabilitation (Wallace *et al.*, 2007:1372). The researcher agrees with this statement and found little documentation on the daily experiences of patients or their family members in an acute rehabilitation programme, with this study striving to fill that gap. Through her experience gained as a social worker in a Life Rehabilitation Unit, the researcher found that family members and patients experience a great deal of trauma when a disabling condition is diagnosed. Winterhalter (2001:227) states that people sometimes have profound psychological reactions to the diagnosis of a disabling condition. The researcher believes that the above statement also applies to family members. The researcher also found that because of the cognitive and physical limitations resulting from a TBI, family members require a great deal of support and education to enable them to come to terms with what has happened.

Wallace *et al.* (2007:1372) advises that family members are able to provide valuable input into the daily experiences of the patients. Prigatano (in Mokhosi & Grieve, 2004:303) reports that the cognitive, emotional and behavioural deficits following TBI are not only problematic for the injured person, but also cause a great deal of trauma for their families and significant others. On this basis, the researcher believed that by conducting a qualitative study with the family members of TBI patients, she would not only gain valuable insight into the experiences of family members of patients with traumatic brain injuries, but would also gain a better understanding of TBI as a whole. The researcher further believes that by completing this study, she can contribute to improved intervention, in addressing the emotions and needs not only of TBI patients, but of their family members as well.

Winterhalter (2001:230) states that as soon as the initial shock has worn off, patients in rehabilitation can become preoccupied with their perceived losses. Through her experience of working with family members of TBI patients, the researcher has

observed that this has a profound effect on the family members as well, especially when one views the family as an integrated system. To gain insight into what these family members are experiencing, the researcher decided to focus on the experience of having a family member with a traumatic brain injury. According to Kathy Wundrum (former Acting National Rehabilitation Manager for Life Healthcare), Nina Strydom (Rehabilitation Standards Manager for Life Healthcare) and Susan Larney (author of the book “Nuwe lewe na ‘n breinbesering”), this would be a very valuable study not only for social workers, but for all professionals working in the rehabilitation field. Wundrum (2009) advises that during rehabilitation, the family is central to the recovery level and adjustment of the person with TBI. She adds that while there are some very good post-acute services out there to support the families of people with TBI, there is very little indeed to support those going through the acute experience. She sees this study as fitting into the body of knowledge very effectively and that Life Rehabilitation has a responsibility and opportunity to offer better socially-oriented services during the acute stages. The first step would be to find out what the needs are, what the current experience is and what Life Rehabilitation should be doing differently and additionally.

“Traumatic brain injury accounts for more than a third of all deaths resulting from injuries. With more effective medical rescue and evacuation services and developments in the field of neurosurgery, the rate of survival after trauma has increased dramatically” (Nell & Brown and WHO Collaborating Centres for Neurotrauma in Mokhosi & Grieve, 2004:301). According to Nell and Ormond-Brown (in Schultz, n.d.:2), the 2001 Census reports that the prevalence of disability in South Africa shows that 5% of a population of 44.8 million are disabled. It does however not make any provision for a sub-category of TBI. Nell and Ormond-Brown (in Schultz, n.d.:2) further report that an average of 316 in 100 000 cases of TBI are reported per year. If this average is used, an estimated 141 568 cases (based on a population of 44.8 million) are reported per year (Schultz, n.d.:2). The author further comments on the demographic profile of persons who have suffered a TBI. The Schneider *et al.* (1999 CASE) and Nell and Ormond-Brown (in Schultz, n.d.:2) cases were used to compile a list of characteristics of persons in a high risk group for a brain injury: The following were identified as high risk groups: African and coloured men in the age group of 25-44 years. The highest risk group for the white and coloured population would be 15-25 years of age. The author further states that the Indian population

carries a very low risk of brain injury, but does not elaborate on the reason (Nell and Ormond-Brown in Schultz, n.d.:2). It must be noted that these studies were conducted in 1991 (in South-Africa) and according to Schultz (n.d.:3) it can be assumed that the statistics have changed significantly over the years. Mokhosi and Grieve (2004:301) state that as in other developing countries, it is estimated that South Africa's incidence of TBI is higher than the worldwide average. A rate of 316 per 100 000 a year has been reported for the Johannesburg area. Statistics of the Life Rehabilitation Unit, where the researcher is currently working, also show that most of the TBI patients admitted are males between 15 and 30 years of age. Segun (2007) states that the prevalence of TBI is not well documented because most cases are not fatal and many patients are not hospitalised. In the United States of America, the leading cause of traumatic brain injury is motor vehicle accidents and in the UK it is the third most common cause, after falls and assaults (Segun, 2007). While there are more specific statistics in South Africa, the researcher is of the opinion that violent attacks, motor vehicle accidents and pedestrian accidents are the main causes of traumatic brain injuries. This opinion is based on the researcher's observations in a Life Rehabilitation Unit over the last three years.

According to the World Health Organisation, traumatic brain injury will be the leading cause of death and disability by the year 2020. An estimated 10 million people are affected annually by TBI and the burden of mortality and morbidity on society leads to traumatic brain injuries being a pressing public health and medical problem. This places a burden on society, because of not only its financial implications but also the effect it has on individuals and their families (Mokhosi & Grieve, 2004:301; Hyder, Wunderlich, Puvanachandra, Gururaj & Kobusingye, 2007:341). Patterson & Staton (2009:149) state that TBI causes "irreparable harm to individuals and have profound effects on families and communities". The researcher believes that the profound impact TBI has not only on individuals but on families and communities, makes it an important issue for social workers working in the field of medical rehabilitation. The lack of support services in post-acute rehabilitation necessitates the empowerment of family members so that they can take over the care of the patient. In order to support and fully empower them for the journey ahead, social workers should first understand what family members are experiencing before recommendations for continued care are made.

In view of the rationale discussed and information provided above, the researcher sees the completion of this study as imperative for the field of social work and other helping professions in the rehabilitation of people with traumatic brain injuries and supporting the family in this long-term journey.

1.2 Problem formulation

The Brain Injury Association of America reports that globally every 23 seconds someone in the USA sustains a TBI and more than 5.3 million people in the USA require long-term support as a result (Patterson & Staton, 2009:149). Most literature from Africa discusses head injury and not specifically TBI, which makes intercontinental comparisons difficult (Hyder *et al.*, 2007:348). The burden of TBI is however present in all regions of the world and is especially prominent in low- and middle-income countries. Developing countries show more risk factors for TBIs to occur, but are the least prepared to handle them when they do (Hyder *et al.*, 2007:350). Mokhosi and Grieve (2004:302) referred to a study by Nell and Brown that showed that reported cases in the Johannesburg area alone have been higher than the worldwide average. Burns (2008b:160) states that the last decade has shown “a rapid expansion in the provision of acute rehabilitation services for patients with TBI in South Africa”. There has also been an increased awareness of the impairments associated with TBI and recognition of the need for structured therapy programmes to improve functional independence after such an injury. The researcher believes that apart from improving functioning independence, as was stated in the research above, there is a clear need for research focusing on the experience of family members of TBI patients.

Significant emotions are experienced by patients with a traumatic brain injury. The researcher believes that this emotional reaction is also experienced by the family members. This could be even more devastating to the family members, because of the impaired cognitive functions of the injured person. Ross and Deverell (2004:36) state that when individuals are diagnosed with disabling conditions, they experience strong emotional reactions. “Feelings of grief, anxiety, inadequacy, anger, guilt, vulnerability and confusion are some of the more common emotions that clients and their families

experience when they encounter a disability in themselves or a family member” (Ross and Deverell, 2004:41).

The researcher agrees with this statement as she has witnessed patients in the rehabilitation unit and their families in an active bereavement process. After a traumatic brain injury the patient is usually admitted to an intensive care unit (ICU). Once medically stable, able to participate in an active rehabilitation programme and provided this is authorised by the patient’s medical aid, the patient is transferred to a rehabilitation unit. While the patient is in ICU, the outcome is very uncertain and support to the family is often very limited. Patients are often in a coma and unable to communicate. While the researcher was working with TBI patients, she found that family members received very limited support, education on the condition and feedback regarding the patients’ medical state from team members. This made the family members very anxious when patients were eventually transferred to a rehabilitation unit. In this study, the researcher would like to focus on the families’ experiences from the time of the patients’ admission to ICU until their discharge from rehabilitation. During the rehabilitation process, family members are encouraged to support the patient in the rehabilitation unit. This is often very difficult for them, since it entails confronting reality and the often devastating impact of the injury.

Once the patient has shown satisfactory progress and is ready for a weekend leave of absence, family training is done in order to enable the family to take the patient home. The researcher has found that families are often very anxious about taking the patient home, as they are unsure how he or she will react and cope. Throughout the process, family members are also confronted with reality in that they have to be involved in the rehabilitation process where the focus remains on the patient’s emotional adjustment and coping and not on the family. In the light of this explanation, this study would like to focus on the experience of family members from the time of their admission into hospital until post discharge. The researcher believes that by gaining an understanding of what the family of a TBI patient are experiencing, she would be able to make recommendations for appropriate intervention and supportive services, not only for the unit where the research is conducted but for Life Rehabilitation as a business nationally.

In a nutshell, the problem in this study concerns the experience and challenges of family members while the patient with a TBI is in hospital and in the rehabilitation unit. The study will therefore seek to understand the experience of family members of patients with TBI, from their being placed in ICU until their discharge from acute rehabilitation. Recommendations for social workers working in the field of the medical rehabilitation of patients with traumatic brain injuries will be made.

1.3 Goal and Objectives of the research study

1.3.1 Goal

According to Fouché (2002:107) the goal is the broader, more abstract concept of the overall end on which the study is focussed. It can also be seen as the overall purpose of the study.

Bless and Higson-Smith (1995:42) state that the goal of exploratory research is to collect insight in terms of a situation, incident, community or an individual. The goal for this study was of an exploratory nature. This study strived to understand the experiences of family members of a traumatic brain-injured patient.

The following goal was formulated as follows:

To explore the experiences of adult family members of their traumatic brain-injured family member's post-acute rehabilitation.

1.3.2 Objectives

Fouché (2002:107) describes objectives as the realistic steps which are completed in a given time in order to achieve the goal.

Objectives of this study are to

- conceptualise traumatic brain injuries (TBI), mechanisms of injury, signs and symptoms, effects of TBI, assessment tools and outcome measures, cognitive rehabilitation and management of long term complications;

- explore adult family members' experiences of their traumatic brain-injured family member post-acute rehabilitation; and
- make recommendations for acute rehabilitation centres and for social workers in intervening with the family members of traumatic brain-injured patients' post-acute rehabilitation.

1.4 Research question

Mouton (2001:48) is of the opinion that research problems should be presented in the form of questions as it is a way of focussing on the problem. Fouché and De Vos (2005:103) add that the researcher must formulate a research question when he or she is conducting a qualitative study.

The research question for this study was: **What were the experiences of adult family members of the post-acute rehabilitation of their family member with a traumatic brain injury (TBI)?**

1.5 Research methods

This was a qualitative study, using applied research, in which the researcher strived to solve problems and assist workers in the management of certain problems. Fouché and Delport (2005:74) state that qualitative research is focussed upon understanding the meaning that people attach to their everyday lives.

The research design that the researcher used is case studies, specifically collective case studies, as she wanted to expand her understanding of the experience of family members of TBI patients. Fouché (2005:272) quotes Stake who argued that "the sole criterion for selecting cases for a case study should be the opportunity to learn." According to Fouché (2005:272) collective case study expands the understanding of the researcher on a social issue or population being studied. "The interest in the individual case is secondary to the researcher's interest in a group of cases."

Eight separate one-to-one interviews were conducted with eight participants, representing 8 different families with a TBI patient as family member. Each participant shared her or his own experience with the researcher, in order to compare and correlate the findings. This in-depth analysis assisted the researcher to explore each of the participants' thoughts and views and as a result, that of their family.

In this study the sample was chosen by means of non-probability, purposive sampling. Strydom and Delpont (2005:329) state that this sampling technique entails the selection of participants with characteristics which will benefit the study. For this study the sampling criteria were as follows:

Participants had to be a **family member** of a patient who

- suffered a traumatic brain injury (TBI);
- underwent acute rehabilitation at Life Eugene Marais Hospital in the last four years;
- completed rehabilitation, in other words, it must be post discharge;
- live in the province of Gauteng; and
- are able to speak and understand English or Afrikaans, irrespective of their gender, race, religion, culture or age.

Possible participants were selected from the patient list at Eugene Marais Rehabilitation Unit. They were contacted telephonically and asked if they would be willing to participate in the study. If they agreed, a date and time was set up for the interview. Firstly, the letter of informed consent was read and discussed and if the participant agreed voluntarily, it was signed. Once agreed, the interview commenced thereafter. A total of eight participants were eventually included in this study, representing eight different TBI patients and their families. Every participant was debriefed after the interview.

Data was collected through one-to-one semi-structured interviews, using an interview schedule. Seidman (in Greeff, 2005:286) states that the researcher will make use of an interview, as there is an interest in the participants' life stories. For the purpose of this study, a semi-structured interview was used (Greeff, 2005:296). The author adds that

researchers use semi-structured interviews, “in order to gain a detailed picture of a participant’s beliefs about, or perceptions or accounts of, a particular topic.” This type of interviewing gave the researcher more flexibility to ask questions and to explore the experience of the participants. An interview schedule was used to guide the interview and the research interviews were held in the office of the social worker at Life Eugene Marais Hospital, Pretoria or at the participant’s home. The choice of venue was given to the participants. Interviews held at the Hospital were private and confidential in the office of the researcher and when held at the participant’s home, privacy was ensured by conducting it in a private room. This study allowed the researcher to enter into the lives of these family members, and to gain insight into their world of living with a family member with a TBI. The researcher digitally recorded the interviews with the permission of the participants. Interviews were conducted in Afrikaans (all the participants were Afrikaans-speaking).

The researcher transcribed the digitally recorded interviews and then analysed the contents according to the themes and sub-themes that emerged from the data. The data revealed the participants’ experiences and the researcher has placed their verbatim responses within quotation marks in chapter 4 in order to present a verbatim account of what they have said.

Creswell (in De Vos, 2005:334) states that the best way in which the process of data analysis and interpretation can be presented is in a spiral form. The researcher worked in analytical circles, rather than taking a linear approach. Data was analysed according to the process as described by Creswell (in De Vos, 2005:334).

A detailed description of the research methodology used in this study, including further detail on data collection and analysis, will be provided in Chapter 3.

1.6 Pilot study

“In qualitative research, the pilot study is informal and a few participants possessing the same characteristics as those of the main investigation can be involved in the study, merely to ascertain certain trends” (Strydom and Delpont, 2005:331). A pilot study was

completed with two participants. These two participants met the same sampling criteria as the participants of the main study. These participants did not form part of the main study, but were interviewed in the same manner as which the participants in the main study would, to ascertain if any adjustments should be made to the interview or interview schedule, way the interview is conducted, the time allowed for the interview, the recording equipment, privacy and venue during the interview or any other component of the interview. After the pilot study, the researcher did not find it necessary to make any adjustments, but it did assist her to come into the habit to allow for longer silences for participants to reflect on what was being said. She further found that the recording equipment worked well, the participants who were selected for the pilot study, seemed to feel at ease with the privacy of the office and she was able to stay well within the limits of the time allocated for the interviews.

1.6.1 Feasibility of the study

The researcher worked as a social worker in the Life Eugene Marais Rehabilitation Unit. The Rehabilitation Unit has been operating since 2006 and during this time researcher has conducted interviews with many TBI patients and their families. The researcher was therefore able to gain access to the client/patient base easily. The Rehabilitation Standards Manager gave provisional permission for this study and full authorisation was granted upon proof of ethical clearance. The researcher received good support from the unit and management to conduct this study, as the findings would be valuable for service delivery, not only for the Eugene Marais Unit, but also for the other rehabilitation units in the Life Rehabilitation Group. The researcher used to work full time, but decreased her hours and later stopped working all together to accommodate the time that it took to complete this study. The interviews were conducted at Life Eugene Marais Rehabilitation Unit, or if participants preferred it, at their homes. If there was transport costs involved, the researcher covered it. Printing costs of the dissertation were also covered by the researcher.

1.6.2 Testing of the data collection instrument

Strydom and Delpport (2005:331) describe the pilot study as an informal process that entails a few participants that have the same qualities as the participants of the main study, but will not participate in the main study. The purpose of the pilot study was to test whether the researcher could collect the data that were needed for the study. A pilot study was completed with two participants. Two participants who were adult family members of patients were chosen from the case load list of the unit. For the purpose of this study, the pilot study was mainly used to determine which problems the researcher should prepare for when conducting the main study. It was also to assist the researcher to ascertain if the chosen data collection method was the most appropriate one for this study. These participants did not form part of the main study. Any recommendations made for the interview or interview schedule, was taken into consideration and changes were made if needed.

1.7 Trustworthiness

Morse and Richards (in Strandberg 2009:283) and Lincoln and Guba (in De Vos, 2005:346) propose the following assumptions of the qualitative paradigm:

- *Credibility*- which was the inquiry of the study. “An in-depth description showing the complexities of variables and interactions will be so embedded with data derived from the setting that it cannot help but be valid.” The researcher prepared herself well for interviewing in order to be able to obtain the richest data from it. During the presentation of themes and sub-themes, the researcher planned to provide the verbatim quotes in Afrikaans (the original language the interviews were conducted in) and to provide a translation into English thereafter. This was planned because the researcher believes that some of the meaning might change in translation. Some emotions and descriptions are just too difficult to be translated without changing some of its meaning. Lincoln and Guba (in Shenton, 2004:64) state that credibility is one of the most significant factors in establishing trustworthiness. The author suggest that strategies be used to ensure honesty from participants by providing them with the option to refuse to

participate and to withdraw whenever they want to and thus only involve those who are really willing to participate and offer data freely (Shenton, 2004:66). Furthermore participants should be assured that there are no right or wrong answers. During this study the researcher planned to adhere to the principles explained above.

- *Applicability*- entails the transferability of the results. According to De Vos (2005:346) transferability is sometimes seen as a weakness of the qualitative approach. The researcher planned to use data from multiple cases and informants to strengthen the study's usefulness for other settings. The researcher constantly referred back to the theoretical framework of data collection and analysis to guide the study. Having firm roots in the theory, the researcher believes that she was able to assure transferability.
- *Consistency*- entails the dependability of the results. The researcher felt that to expect that the social setting of rehabilitating patients should remain unchanged was unrealistic. In the conducting of the study she was however diligent to remain open to possible changes. Some participants indicated that they would like to be interviewed in their homes and not in the unit. These participants' wishes were honoured. So the only inconsistency was that some participants were interviewed in the unit and others were interviewed in their home.
- Lincoln and Guba (in De Vos, 2005:346) explain each assumption and add a fourth: *Conformability*: This captures the traditional concept of objectivity. The researcher planned a detailed literature review not to evaluate herself, but to rely solely on the data and then to substantiate it with the literature.

According to Johnson (1997:283), one potential threat is researcher bias. This tends to happen by selective observation and recording of information and allowing one's personal views to affect how data is interpreted. One way of understanding researcher bias is by reflexivity, a process during which the researcher completes critical self reflection about his or her biases. The researcher thought a lot about her own perceptions and views regarding the field of study in order to identify her own biases. She has worked for a number of years in a rehabilitation setting, but has only had contact with people with traumatic brain injuries and their families during their short period of rehabilitation. There was usually no contact after rehabilitation, thus leaving

the researcher without any understanding of the bigger picture of what family's experience post rehabilitation. She was aware of her own understanding of what problems arise during rehabilitation and tried her best to not let that influence the process. This could be a result of having met or known the participants from working in the unit previously, as either a social worker or later as a therapy manager. This made the interviews difficult, as participants had the need for counselling about the difficulties they were experiencing and also wanted information or help to deal with troublesome situations. The researcher tried to stay focussed as a researcher, but found it difficult to deal with these expectations participants had of counselling, even though it was clearly spelt out prior to interview that the focus was for research purposes only. Researcher dealt with this during the debriefing of each participant after the interview and referred them to the current social worker at the unit, if it was needed. The process of negative case sampling was used as explained by Johnson (1997:284) where the researcher disconfirms their expectations and explanations about what they are studying. The researcher tried to enter into interviewing without any expectations what she will find.

Johnson (1997:286) includes the use of theoretical validity (where a theoretical explanation from the literature study is used to explain the data), extended fieldwork (a sufficient amount of time is spent studying research participants and their setting in order to gain confidence that the patterns of relationships are stable and the researcher can understand why they occur) and theory triangulation (where the phenomenon being studied and the fact that it could be explained by different theories are examined).

A full description on how the above was implemented will follow in Chapter 3.

1.8 Ethical issues

Neuman (2000:90) states that ethical issues can be seen as concerns, dilemmas or conflicts. He further states that ethical issues define the correct way in which to conduct research. Ethical refers to what is legally right or what is morally the correct way of working. The researcher took the following ethical issues into consideration:

1.8.1 Avoidance of harm

According to Strydom (2002:64) it is possible to do harm to a participant on a physical or emotional level. It was further added that participants must be educated on the possible impact of the study before commencement of the study. The researcher did not act as therapist in this study, but did debriefing following completion of the interview. She referred participants for further counselling if it was necessary. A social worker was identified to counsel participants should they need counselling. The researcher was aware of the fact that it would be easy to become involved in addressing the emotions of the participants, but had prepared herself to stay focussed as researcher and only document the emotions of the participants.

1.8.2 Informed consent

Informed consent implies that all possible and proper information regarding the purpose of the study, the procedures to be followed, and possible advantages, disadvantages and dangers have been communicated to all possible participants of the study. The author focused on the accuracy of the information provided in order for the potential participants to make a voluntary, well-considered decision regarding participation in the study (Strydom, 2002:65). Neuman (2000:96) states that this process can be made easier by drawing up a written permission document. For this study the researcher compiled a letter of informed consent that explained the goal and process of the study, as well as assurance of confidentiality and anonymity. This was done to assist participants in making an informed decision. Participants were also given the opportunity to withdraw from the study at any point. The written document forewarned the participants that the interviews would be tape recorded. They were also informed that the data would be stored for 15 years, as required by the University for archival purposes. The researcher kept a copy of the signed letters of informed consent and provided participants with a copy.

1.8.3 Violation of privacy/ anonymity/ confidentiality

According to Strydom (2005b:61) privacy refers to personal privacy while confidentiality refers to the “handling of information in a confidential manner”. Confidentiality was

ensured by referring to participants by alphabet letters, for example participant A. The researcher watched over information that was entrusted to her, in order to protect the right of the participant. Recordings and transcripts were only handled by the researcher and all care was taken to ensure that no other person had access to these recordings and transcripts. Strydom (2005b:62) states that anonymity is that no person, including the researcher should be able to identify any subject afterwards. Due to the researcher performing the interviews herself, she was not able to secure anonymity.

1.8.4 Actions and competence of researchers

Strydom (2002:69) states that the researcher is ethically obliged to ensure that he or she is competent and has the necessary skills to conduct the research. The researcher is of the opinion that she was competent to conduct the interviews, as conducting interviews on a daily basis was part of her job description as social worker. It was however realised that these interviews would only focus on understanding the emotions of participants and not on the delivery of support services. The researcher has completed a research study as part of her undergraduate studies and has also attended and successfully completed a postgraduate module on research methodology. On this basis, she felt confident that she was competent to complete this research study and she was also guided by her competent supervisor at the University.

1.8.5 Release or publication of the findings

Strydom (in Strydom, 2002:71) states that the findings of the study must be presented to the public in written form, otherwise even a highly scientific study will be of little meaning and wouldn't be considered as research. The researcher presented the final research report as accurately as possible and took extra care to ensure that all sources were correctly referenced. The dissertation was made available to the University of Pretoria library and a copy was provided to Life Rehabilitation. An article with the researcher's supervisor as co-author will be submitted for publication in an accredited journal.

1.9 Definition of key concepts

Dubin (in De Vos, 2002:29) states that all aspects that form part of a scientific discipline, must have a clear description or explanation. Accordingly the following terms are presented:

1.9.1 Rehabilitation of people with disabilities

Rehabilitation refers to the processes of helping a person achieve the highest level of function, independence, and quality of life possible. The word is derived from the Latin word "habilitas," which means to make able (University of Virginia Health System, 2004). Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination (Rehabilitation, [sa], n.d.).

Miller and Keane define rehabilitation as “the process of restoring a person’s ability to live and work as normally as possible after a disabling injury or illness” (in Sigurgeirsdottir & Halldorsdottir, 2007: 385).

For the purpose of this study, rehabilitation of people with disabilities is the process whereby a person with a traumatic brain injury is admitted to an acute setting where holistic team-orientated therapy is focussed on optimal physical, functional, psychological and social retraining in order for that person to return to a lifestyle that is as functionally independent as possible.

1.9.2 Traumatic brain injury

According to Segun (2007), traumatic brain injury (TBI) is a nondegenerative, noncongenital insult to the brain from an external mechanical force, possibly leading to permanent or temporary impairment of cognitive, physical, and psychosocial functions with an associated diminished or altered state of consciousness.

Traumatic brain injury is any injury of a traumatic nature that directly or indirectly causes damage to the brain. The authors distinguish between two types of injuries namely focal contusions and diffuse axonal damage. A focal contusion is bruising of

the brain as a result of a direct blow to the head. Diffuse axonal damage is the result of a twisting, tearing or stretching of the axons of the nerves fibres in the brain (Pulaski, 1998:668).

For the purpose of this study traumatic brain injury is seen as any injury to the brain that was traumatic in nature and lead to permanent or temporary physical, cognitive, communicative and psychosocial impairments.

1.9.3 Family members

This refers to any individual related to a person by blood, marriage, or adoption (Definitions and Acronyms, 2008:3). It could be a group of people related by heredity, such as parents, children, and siblings, but the term can sometimes be broadened to include persons related by marriage or those living in the same household, who are emotionally attached, interact regularly, and share concerns for the growth and development of the group and its individual members (Mosby's Medical Dictionary, 2009).

For the purpose of this study, family members was seen as adult family members of the traumatic brain-injured person by heredity, marriage, adoption or living in the same household, who were emotionally attached and interact regularly.

1.10 Limitations of the study

- There is a scarcity of literature in the field of Social Work on this topic. Literature from other disciplines was consulted and adapted;
- Only eight participants were selected for this study and after interviewing them a point of data saturation was reached, thus not needing to sample more participants. The findings of this study can therefore not be generalised.
- The researcher wanted to conduct a second interview with all eight participants to ensure trustworthiness, but participants indicated in the main study that they were extremely busy and struggled to find the time to conduct the interview with the researcher. None of them had any help and they were the primary caregiver

of their family member with a TBI and therefore a second interview was not feasible;

- Due to the difficulties family members had to arrange alternative care of their family member with a TBI to participate in the interview, the researcher felt pressurised to keep the interviews as short as possible;
- All participants knew the researcher before the study, some in the capacity of social worker and others in the capacity of rehabilitation therapy coordinator. The researcher held these two positions over the almost five years that she worked in the Rehabilitation Unit. This made the interviews difficult, as participants had the need for counselling about the difficulties they were experiencing and also wanted information or help to deal with troublesome situations. The researcher tried to stay focussed as a researcher, but found it difficult to deal with these expectations participants had of counselling, even though it was clearly spelt out prior to interview that the focus was for research purposes only. The researcher dealt with this during the debriefing of each participant after the interview and referred them to the current social worker at the unit if it was needed. The researcher also tried her best to avoid researcher bias as a result of the above and strived towards ensuring trustworthiness as discussed earlier.

1.11 Contents of the Research Report

Table 1: Contents of the research report

Chapter 1	General introduction and research methodology
Chapter 2	Literature study of traumatic brain injuries (specific focus areas: traumatic brain injuries, acute rehabilitation and emotional journey of patients with traumatic brain injuries, and family members)
Chapter 3	Empirical study
Chapter 4	Summary, conclusions and recommendations

Subsequently, chapter two will discuss traumatic brain injuries, the reactions of family members, a rehabilitation unit, the role of the social worker.

CHAPTER 2

TRAUMATIC BRAIN INJURY (TBI), EXPERIENCES OF THE FAMILY AND THE REHABILITATION UNIT

2.1 Introduction

A traumatic brain injury (TBI) is as its name suggests: an extreme traumatic event that affects the most powerful but fragile organ that controls all our bodily functions and that holds the essence that makes individuals unique. Some patients with a traumatic brain injury will recover without realising what the effect could have been and others will be left with effects that will have a lasting effect on their lives. “Many sufferers will remain severely incapacitated and a lamentably large number will become part of the statistics on the mortality after TBI”. (Burns, 2008a:76). According to Mazaux and Richer (1998:435) many will survive but as a result have a disabling condition.

According to Burns (2008c:163) recent years have seen an increased interest in TBI as more patients survive severe injuries. This has led to advances in knowledge and treatment of patients with TBI and rehabilitation is increasingly recognised as an important step in the recovery process. She continues to state that “it is also evident that a comprehensive programme of family and caregiver education and supportive counselling during the rehabilitation process is of vital importance in order to achieve maximal outcomes and successful reintegration into social and community settings”.

According to El-Gindi and Abdel-Azeem (2001:4) Africa is currently not only facing a civil and regional war but also road wars between moving vehicles and innocent and productive population on the other, leading to a large number of mortalities and tremendous economic loss. The authors continue to state that in Africa, road traffic accidents are responsible for the majority of head and spinal injuries. Upgraded road quality resulted in excessive speed and careless driving and thus to an increased death toll (El-Gindi and Abdel-Azeem 2001:5). Through her work experience in an acute rehabilitation setting, the researcher can agree as most TBI patients that were seen were involved in a motor vehicle accident.

According to Flanagan (in Sinnakaruppan and Williams, 2001:653) TBI has been found to be mainly amongst younger people. This complicates rehabilitation and family coping as it means that the caregivers (which are mainly parents) will be required to provide a lifetime of care and support. Depompei & Zarski and Kreutzer, Marwitz and Kepler in Kreutzer, Gervasio and Camplair (1994:197) state that there is insufficient empirically derived information on the family's response to TBI. Such information can be used to train rehabilitation personnel, enable programmes to address the family and patients' concerns and needs and provide general understanding about family adaptation in these stressful circumstances. Even though this statement was from an article in 1994, the researcher found little to no research articles that were done in a South African context, except for the study by Drenth (1991) on the psychosocial implications of a head injury for the patient and his family. She also focussed on the task of the social worker. Through her clinical experience in a South African rehabilitation unit, the researcher has found that rehabilitation personnel know little about the experience of the family. More focus is placed on the experience of the person with TBI and there is limited understanding in what the family experiences and how they can be supported. The researcher believes that this study will provide insight into the experience of the family in order to adjust work programmes to not only provide in the needs of the person with a traumatic head injury, but also to include the family members and caregivers.

This chapter will focus on traumatic brain injuries and the effects thereof, on the emotional journey of patients and family members, and on acute injury rehabilitation.

2.2 Definition of key concepts

2.2.1 Rehabilitation

“Rehabilitation is the process of helping a person to reach the fullest physical, psychological, social, vocational and educational potential consistent with his or her physiologic or anatomic impairment, environmental limitation and desires and life plans”, according to De Lisa, Currie and Martin (in Burns, 2008b:84).

Miller and Keane define rehabilitation as “the process of restoring a person’s ability to live and work as normally as possible after a disabling injury or illness” (in Sigurgeirsdottir & Halldorsdottir, 2007: 385).

For the purpose of this study, rehabilitation will be seen as the acute process in an in-hospital rehabilitation unit where the person with a TBI will be involved in a daily therapeutic programme, focussing on returning to the highest possible functionally independent level.

2.2.2 Traumatic brain injury (TBI)

TBI is defined as damage to the brain caused by trauma that was externally inflicted to the head and may result in significant impairment of an individual’s physical, cognitive and psychosocial levels (Burns, 2008a:76).

Segun (2007) gave the following definition: Traumatic brain injury (TBI) is a nondegenerative, noncongenital insult to the brain from an external mechanical force, possibly leading to permanent or temporary impairments of cognitive, physical, and psychosocial functions with an associated diminished or altered state of consciousness.

Traumatic brain injury is any injury of a traumatic nature, that directly or indirectly causes damage to the brain. The authors distinguish between two types of injuries namely focal contusions and diffuse axonal damage. A focal contusion is bruising of the brain as a result of a direct blow to the head. Diffuse axonal damage is the result of a twisting, tearing or stretching of the axons of the nerves fibres in the brain (Pulaski, 1998:668).

For the purpose of this study traumatic brain injury will be seen as any injury to the brain that is traumatic in nature and leads to permanent or temporary physical, cognitive, communicative and psychosocial impairments.

2.2.3 Family carers

“Family carers are defined as those people who are related to a head-injured individual and perform a major unpaid caregiving function” (DeJong, Batavia and Williams in Sinnakaruppan & Williams, 2001:654).

“One who contributes the benefits of medical, social, economic, or environmental resources to a dependent or partially dependent individual, such as a critically ill person” (Mosby’s Dictionary, 2006:313).

For the purpose of this study, family carers will refer to family members who resume all caregiving activities of a person with a TBI without any monetary compensation.

2.2.4 Cognition

Cognition refers to a person’s thinking and memory skills. Cognitive skills include attention and concentration, level of awareness of one’s surroundings, organising, planning, following through on decisions, problem-solving skills, judgement, reasoning and awareness of problems. Memory skills include the ability to remember things before and after the brain injury. Because of the damage caused by a brain injury, some or all of these skills will be changed (Family guide to..., n.d).

Cognition includes all mental activity involved in knowing and the mind’s functioning: perception, attention, memory, imagery, language functions, developmental processes, problem solving and artificial intelligence (Corsini in Farahmand, 2001:241).

For the purpose of this study cognition refers to the skills of the mind, including attention, concentration, problem solving, cognitive communication skills, memory, awareness, organising, sequencing and orientation.

2.2.5 Attention

Burns, (2008c:160) gives the following definition of attention:

Attention may be considered to be the selective channelling of arousal. It includes the ability to focus attention on certain stimuli (focus or selective attention), to sustain attention over time, to filter out distracting influences, to switch attention between two or more task demands and to shift attention in line with changing goals and priorities.

“Attention is the element of cognitive functioning in which the mental focus is maintained on a specific issue, object, or activity” (Mosby’s Dictionary, 2006:166).

For the purpose of this study attention is regarded as the cognitive process of focussing on one aspect while being able to block out all other.

2.2.6 Executive functions

Executive functions are those cognitive functions that assist us to adapt to change, solve unexpected problems, anticipate outcomes and generally cope with situations that fall outside of normal routines (Burns, 2008c:161).

Executive functions are ideation and concept formation, judgement, abstract thought and intellectual functions (Pulaski, 1998:661).

For the purpose of this study, executive functioning will refer to cognitive abilities that fall outside normal daily routines and include judgement, abstract thinking, solving unexpected problems and adapting to change.

2.2.7 Perseveration

“Perseveration refers to a tendency to repeat a behaviour pattern over and over irrespective of the context or stimulus and is a common and major characteristic of brain damage manifest in all modalities” (Code, 1989:166). Hudson (in Gotts and Plaut, 2004:323) describes perseveration as “...the inappropriate repetition or continuation of a previous utterance or response when a different response is expected”

For the purpose of this study, perseveration refers to a tendency to repeat words, phrases and actions when a different response was expected.

2.3 List of medical terms

Anterograde amnesia

“The inability to recall events that occur after the onset of amnesia and the inability to form new memories” (Mosby’s Dictionary, 2006:111).

Confabulation

“The fabrication of experiences of situations, often recounted in a detailed and plausible way to fill in and cover up gaps in memory. The phenomenon occurs principally as a defence mechanism and is most commonly used by alcoholics, especially those who have Korsakoff’s psychosis, and persons with head injuries, amnesic disorders, dementia or lead poisoning” (Mosby’s Dictionary, 2006:440).

Diffuse

“Becoming widely spread, such as through a membrane or fluid” (Mosby’s Dictionary, 2006:561).

Dysarthria

“Difficult, poorly articulated speech, resulting from interference in the control and execution over the muscles of speech, usually caused by damage to a central or peripheral motor nerve” (Mosby’s Dictionary, 2006:602).

Extubation

Extubation is “the process of withdrawing a tube from an orifice or cavity of the body” (Mosby’s Dictionary, 2006:698).

Intubation

Intubation is the “passage of a tube into a body aperture, specifically the insertion of a breathing tube through the mouth or nose into the trachea to ensure a patent airway for the delivery of anaesthetic gases and oxygen or both” (Mosby’s Dictionary, 2006:1012).

Gait

“The manner or style of walking, including rhythm, cadence, and speed” (Mosby’s Dictionary, 2006:779).

Haemorrhage (Hemorrhage)

“A loss of a large amount of blood in a short period, either externally or internally. Hemorrhage may be arterial, venous or capillary” (Mosby’s Dictionary, 2006:872).

Hemiparesis

“Muscular weakness on one half of the body” (Mosby’s Dictionary, 2006:866).

Hemiplegia

“Paralysis of one side of the body. Kinds of hemiplegia include cerebral hemiplegia, facial hemiplegia and spastic hemiplegia” (Mosby’s Dictionary, 2006:866).

Kinaesthesia

“The perception of one’s body parts, weight, and movement” (Mosby’s Dictionary, 2006:1045).

Neuron

“The basic nerve cell of the nervous system, containing a nucleus within a cell body and extending one or more processes. Neurons can be classified according to the direction in which they conduct impulses or according to the number of processes they extend” (Mosby’s Dictionary, 2006:1284).

Posttraumatic amnesia

“A period of amnesia between a brain injury resulting in memory loss and the point at which the functions concerned with memory are restored” (Mosby’s Dictionary, 2006:1504).

Proprioception

“One’s own sensation pertaining to stimuli originating from within the body related to spatial position and muscular activity or to the sensory receptors that they activate” (Mosby’s Dictionary, 2006:1538).

Retrograde amnesia

“The loss of memory for events occurring before a particular time in a person’s life, usually before the event that precipitated the amnesia. The condition may result from disease, brain injury or damage, or a traumatic emotional incident” (Mosby’s Dictionary, 2006:1628).

Spasticity

“A form of muscular hypertonicity with increased resistance to stretch. It usually involves the flexors of the arms and the extensors of the legs. The hypertonicity is often associated with weakness, increased deep reflexes, and diminished superficial reflexes” (Mosby’s Dictionary, 2006:1742).

Spatial relationships

“Orientation in space; the ability to locate objects in the three-dimensional external world using visual or tactile recognition and making a spatial analysis of the observed information” (Mosby’s Dictionary, 2006:1742).

Synapse

“The region surrounding the point of contact between two neurons or between a neuron and an effector organ, across which nerve impulses are transmitted through the action of a neurotransmitter, such as acetylcholine or norepinephrine. When an impulse reaches the terminal point of one neuron, it causes the release of the neurotransmitter. The neurotransmitter diffuses across the gap between the two cells to bind with receptors in the other neuron, muscle, or gland, triggering electrical changes that either inhibit or continue the transmission of the impulse” (Mosby’s Dictionary, 2006:1806).

2.4 Theoretical framework

For this study, the researcher chose to work from the biopsychosocial model. According to Ross and Deverell (2004:12), this model focuses on the promotion and maintenance of health through environmental and behavioural changes. It places an emphasis on the role of people’s behaviour, how they lead their lives and their access to health services to determine their health status. Gilbert (in Ross and Deverell, 2004:12) see prevention, management of illness and comprehensive rehabilitation as more appropriate than intervention. This framework further views people as being able to participate in their recovery rather than passive victims of a disease. This model further encourages the caregiver to not only focus on the patient, but on the family and significant others in the environment. Consideration is given to the effect of the illness on others. The researcher found this model applicable due to the nature of TBI. The focus with TBI patients is initially on the medical treatment and rehabilitation, but as the patient moves through the rehabilitation, the psychological and behavioural issues become more evident, especially once home after discharge and even more so together with the social and relationship changes amongst friends and family. The effects of the TBI cannot be changed or treated with medication and therefore environmental and behavioural adaptations have to be made. This study specifically focuses on the experience of family members and significant others and the results of the study can assist service providers to adapt their rehabilitative and supportive

services. This ties in well with the framework to include family and significant others in the process. Environmental factors such as income, work, their access to health services and their behaviour are also included.

2.5 The human brain

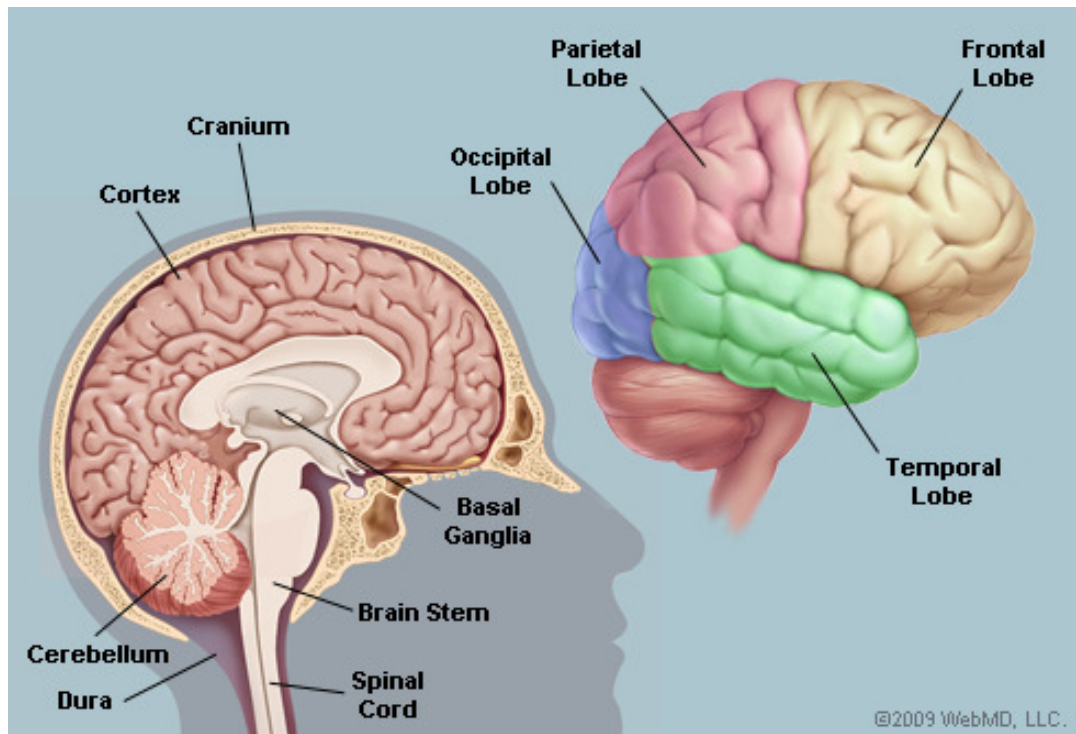
It is important for professionals working with traumatic brain injury to understand normal brain function. It is also important to view a person with a TBI in the context of his familial and social environment and to keep in mind that TBI is a unique experience for every individual (Scott and Dow, 1997:705). The researcher is of opinion that working in the field of acute rehabilitation; this is very difficult as there is no glimpse of what the individual was prior to the TBI.

Pulaski (1998:661) states that while examining different parts of the brain to understand how the brain functions and influences behaviour is valuable, it portrays an incomplete picture of how the brain really works. How the brain functions as a whole is not yet fully understood. Categorisation of the brain by lesion site is therefore not perfect but it does provide some direction about the impairment that might be seen during observation. Various areas of the brain are involved in controlling different performance components. When dealing with a patient that was involved in a traumatic brain injury, it is important to understand what areas of the brain and what functions have been affected (Pulaski, 1998:661). The researcher will provide a short description of the different areas of the brain and if injured what function will be affected. Only a short description will be provided, because as a social worker, the researcher is of the opinion that this is sufficient knowledge required by a social worker.

The frontal lobes are involved for executive functioning, personality, intention and execution of voluntary motor function, voluntary eye movements and programming of the motor component of speech. The frontal lobes are also related to the sequencing, timing and organisation, initiation and planning of action and behaviour. Frontal lobes are also involved in emotions. The parietal lobes are involved in reception of somatic sensation (fine touch, pain and temperature, proprioception, kinaesthesia), perception and interpretation of sensory information. These lobes are also responsible for the comprehension of language and pragmatics. The occipital lobes are responsible for

visual reception and integration of visual information. They assist with the perception of visual-spatial relationships and the formation of visual memory. The temporal lobes are involved in auditory reception and comprehension. They assist with the perception of sound and music. They are also responsible for memory, and the learning of visual and auditory patterns. The temporal lobes are related to emotions, motivation and personality. “The limbic lobes are intimately involved in emotion and memory through their connections to the medial aspects of the frontal and temporal lobes. The exact function of the limbic lobes is not well understood” (Pulaski, 1998:661-663). The brain stem is responsible for controlling eye movements, facial movements and spontaneous breathing. The brain stem also has input into the auditory nerve and thus can affect balance and equilibrium. The cerebellum is the centre for controlled coordinated movements. It makes sure the muscles contract at the right time, with the right amount of force for the activity, to produce the right amount of movement. The cerebellum also stores information for remembering motor programs and also influences balance (Pulaski, 1998:661-663).

Figure 1: Anatomy of the brain



(Brain and nervous..., 2009).

This figure shows the different areas as explained above and where the different areas in the brain are situated.

2.6 Traumatic brain injuries

Traumatic brain injuries have different life changing effects and the researcher would like to focus on these effects. As will be clearly demonstrated, these effects not only impacts on the person with the injury but also on family members and caregivers.

2.6.1 Mechanisms of injury

TBI results from an external force to the brain causing temporary or permanent neurological dysfunction. It is a relatively high-prevalence injury, 10 times more common than spinal cord injury (Khan, Baguley and Cameron, 2003:290). A traumatic brain injury is usually caused by a direct blow to the head or from sudden movements by impacts to other body parts. This can lead to combination of compression, expansion, acceleration, deceleration and rotation of the brain inside the skull (Bakay and Glasauer in Scott & Dow, 1997:706; Burns, 2008a:76). The author (Leech and Shuman in Scott & Dow, 1997:706) continues by saying that brain injuries may be diffuse, focal or both.

Motor vehicle accidents and falls involve acceleration and deceleration with brain rotation inside the skull. The brainstem is more stable than the cerebrum, which rotates around the brainstem during impact. The rotation places a stretch or shear force on the long axons that transmit information throughout the brain and brainstem (Leech and Shuman in Scott & Dow, 1997:706).

Focal lesions can occur anywhere but are usually seen at the anterior poles and inferior surfaces of the frontal and temporal lobes. They occur when the brain hits against the skull and scrapes over irregular bony structures. Due to the smooth surfaces of the occipital and parietal lobes, they are less likely to incur damage. Cranial nerves can also be torn, stretched or contused after a TBI (Burns, 2008a:77; Khan *et al.*, 2003:291). Diffuse injuries are only visible on CT scans in the worst 5-10% of cases and are most commonly seen as “multiple punctate subcortical lesions in and around the corpus callosum and deep white matter and/or as intraventricular haemorrhages”. The most consistent effect on diffuse injuries is altered consciousness. Other clinical markers include absence of a lucid interval and prolonged retrograde and anterograde amnesia.

Head injuries are usually categorised as open or closed. An open head injury is when the skull is penetrated to reveal brain tissue and a closed head injury is when the skull remains intact. These closed injuries can cause more damage that directly affects the brain instead of being partly deflected by the brain tissue (Miller in Patterson & Staton, 2009:150).

The major causes of brain injury include motor vehicle accidents, violence and falls (Burns, 2008a:76). Injuries could equally be as a result of road traffic accidents or falls (Gray, Shephard & McKinlay and Mitchley, Gray and Pentland in Sinnakaruppin & Williams, 2001:654). Younger persons are more likely to sustain a TBI from a road traffic incident and older persons from falls (Sinnakaruppin & Williams, 2001:654). The researcher would like to agree and has observed this in practice.

2.6.2 Physical effects of TBI

All classified brain injuries can involve physical, cognitive, behavioural, psychological, social and recreational symptoms, which vary depending on the area of the brain that is involved in the trauma. It also not only impacts on the person but its consequences often last for months and at times years and therefore the family is left with an adjustment period (Patterson & Staton, 2009:150-151; Uomoto & Uomoto, [sa]:1). It should be noted that impairments resulting from TBI are unpredictable and individualistic (Scott & Dow, 1997:707). A brain-injured person may show any of a number of states of altered consciousness, depending on the severity of the injury (Burns, 2008a:79). It is therefore important not to only take the scans into consideration but also to accommodate unique personal characteristics and the clinical picture. At times, the clinical picture differs from what is seen on scans, as was observed through clinical experience in a South African rehabilitation unit.

Physically TBI can result in gait, balance and coordination problems. The person may also have visual neglect (unawareness of one half of the vision field), diplopia (double vision) and other visual disturbances. Motor problems such as paralysis and inability to use a limb can also occur (Uomoto & Uomoto, [sa]:1). If TBI damages motor pathways or centers, the person can experience weakness on one side of the body. This can be

total (hemiplegia) or partial (hemiparesis). Persons with hemipareses can also have problems with spasticity (a condition in which certain muscles are continuously contracted). This can lead to problems with walking and performing activities of daily living (including eating, dressing, grooming and toileting). People with TBI also have a slowed speed of performance. Further physical effects include poor coordination and slurred speech (dysarthria). Articulation can be affected by different factors but typically involves motor weakness or poor oral motor control (Struchen and Clark, 2007:18-19).

Only the most common physical effects of TBI that have been observed by the researcher have been discussed. The researcher further observed that the physical effects have often been resolved when other effects such as cognitive effects still remain.

2.6.3 Cognitive effects of TBI

Cognitive problems can include limitations in memory, attention, orientation, problem-solving abilities, hand-eye coordination, judgement, insight, reasoning and multitasking (Uomoto & Uomoto, [sa]:1; Struchen & Clark, 2007:19-21; Wikipedia, sv 'traumatic brain injury' and Quintana, 1997:201). Even though cognitive disorders as a result of TBI are very common, few patients are referred to specialised rehabilitation units with cognitive therapy as the primary goal (Burns, 2008c:160). Extensive research has been done on the treatment of physical and medical effects of TBI but further research is needed on cognitive deficits and perceptual visual deficits (Quintana, 1997:201). Alterations in cognition, personality and behaviour are seen as part of the most challenging aspects by therapists working in the field (Whyte, Hart, Laborde and Rosenthal, in Burns, 2008c:160). The author (Burns, 2008c:160) continues to state that physical impairment after a TBI is easily identified and can be determined, but with cognitive deficits it is not that easy. Through experience the researcher is aware that cognitive assessment is an ongoing process and goals need to be adjusted accordingly. There seems to be a perception that if a person with a TBI has made a good recovery physically, he/she has made a good recovery. In practice, the opposite can be the case. Burns (2008c:160) speaks about the "walking wounded" – patients that have made a good recovery physically but are unable to perform the most basic

tasks independently due to their cognitive limitations. At times, even patients that have seemingly made a good recovery are left with cognitive deficits that make them strangers to their family and friends. Therefore cognitive rehabilitative programmes should address not only the physical deficits, but also the psychosocial implications. Through experience, the researcher has found that some family members focus on the physical deficits, as they are more visible and only later (at times after rehabilitation) realise what cognitive deficits there are.

Khan, *et al.* (2003:294) lists the following cognitive impairments after TBI:

- Memory impairment
- Difficulty with new learning
- Attention and concentration
- Reduced speed and flexibility of thought processing
- Impaired problem-solving skills
- Problems in planning, organising and decision-making
- Language problems including reading and writing skills
- Impaired judgement and safety awareness

According to Strub and Black (in Quintana, 1997:216) attention, concentration and memory are the basic processes on which higher cognitive functions are built. According to Burns (2008c:160) and Struchen & Clark (2007:19), limitations in levels of arousal and attention are some of the most common deficits following TBI. Such arousal deficits could lead to poor responsiveness, slow information processing and poor coping with cognitively demanding situations. Attention deficits may lead to poor command following, distractibility, poor task completion, poor error monitoring and confused and disorganised thought patterns. Impulsivity, memory loss and perseveration may also relate to attention disorders. Struchen and Clark (2007:19) include the following attention deficits:

- Trouble focusing attention
- Being easily distracted
- Trouble concentrating while reading
- Difficulty in multitasking
- Difficulty in changing focus

Amnesia is also common and all patients with moderate to severe injuries and most with mild injuries experience it with regards to events immediately preceding (retrograde amnesia) and following the injury (post traumatic amnesia or PTA). Amnesia may clear up to a lesser or greater extent after the initial confusional state wears off. PTA nearly always lasts longer than retrograde amnesia and is a good indicator of the severity of the injury (Burns, 2008c: 161 and Khan *et al.*, 2003:291). Other forms of memory limitations are anterograde memory (difficulty in learning new information), prospective memory (ability to do something in the future) and memory used in explicit, effortful learning (e.g. memorising a list of words). Implicit, automatic learning is often spared after TBI (Burns, 2008c: 161). According to Struchen and Clark (2007:20) slowed information processing is the most common cognitive problem noted after TBI.

The prefrontal area is often injured in TBI and there is evidence that executive functions are dependent on its integrity (Burns, 20058c:161).

Executive functions require complex cognitive skills such as flexibility, reasoning, self-monitoring, self-adjustment of performance, modulation of responses to people and situations, planning, consideration of multiple alternatives and their consequences, and the execution of a plan of action based on all these modalities (Burns, 2008c:161).

Lack of insight into limitations and poor ability to use feedback are all part of the clinical picture. Executive functions are least obvious in highly structured environments such as rehabilitation units and this complicates the accurate assessment of executive functioning. While physical and overt cognitive limitations are easy to see, limitations in executive functioning is more subtle and may only be noticeable over time (Burns, 2008c:161). This may lead to these limitations not being discussed or even picked up in rehabilitation units and the family is often left with the devastating consequences. The researcher has also found that lack of insight into limitations often impacts on the family as they desperately want to have hope and often believe what the person with TBI is saying, leading to the family's poor insight and unrealistic expectations. According to Stuss and Benson (as cited by Gan, Campbell, Gemeinhardt and McFadden, 2006:588), the inability to change and recognise limitations and changes in oneself is one of the most devastating neuropsychological impairments.

At times, persons with TBI have difficulty with visuospatial functioning. This includes difficulty such as attending to things on one side, bumping into things, difficulty recognising shapes and telling the difference between shapes and difficulty finding their way around (Struchen and Clark, 2007:20). Visuospatial impairments are seen less often, probably because posterior regions of the brain is involved and are less likely than frontal and temporal regions to be injured in TBI. Other cognitive impairments (as named above) including problem solving impairments, can also impact on the assessment of visuospatial abilities. Examples of such impairments are visual scanning disturbances, alterations in body schema and impaired perception of form, spatial relations, colour and figure-ground relationships. This has functional consequences in many areas of everyday life such as dressing, grooming, eating, driving, ambulating, and writing (Burns, 2008c:162).

The most common language difficulties experienced by people with a TBI are

- difficulty finding the right words to say what they want to say;
- talking around a topic and never really getting to the point;
- trouble understanding what others are saying;
- difficulty keeping up with a conversation;
- difficulty starting a conversation; and
- talking about topics that are too personal or offensive to others.

(Struchen and Clark, 2007:21).

Cognitive limitations are seen to be longer lasting than physical limitations in the sense that long after the physical scars have healed, these limitations remain and have an impact on various issues including family relationships and returning to some form of employment.

2.6.4 Social, emotional and behavioural limitations

According to the US National Institutes of Health (in Khan, *et al.* 2003:291) it is the “complex neurobehavioral sequelae that produce the greatest disruption to quality of life. Cognitive and behavioural changes, difficulties maintaining personal relationships and coping with school and work are reported by survivors as more disabling than any residual physical deficits”. According to Degeneffe (2001) psychosocial changes after a TBI can impact both behaviour (including impulsivity, agitation, lability, withdrawal and disinhibition) and personality (including depression, anger, denial, passivity, dependency and low self-esteem). Ylvisaker (in Drenth, 1991:38) adds the following personality changes: apathy, decreased motivation, emotional lability, irritability, depression and lack of initiation, disinhibition, low frustration tolerance, increased or decreased reaction of sexual impulses and social immaturity.

“Emotional and behavioural changes will often be very stressful to family members (Uomoto & Uomoto, [sa]:2). According to Burns (2008c:162) psychosocial problems are part of the leading causes of disability in individuals and lead to family stress, relationship failure and vocational handicap.

Such disabilities usually result from a combination of cognitive deficits and behavioural impairments which interact in complex ways with each other; very seldom are behavioural problems present in the absence of cognitive deficits. A disturbed mind state as result of cognitive impairment, in interaction with malfunctioning regulatory systems, can result in a myriad of behavioural disabilities that are often too complex to dissect into cause-and-effect relationships.

Some persons with TBI lack appropriate drive to initiate tasks. Problems with initiation can often be misinterpreted as laziness or as non-compliance. This may accompany particular patterns of neurological damage that disrupt the connection between limbic motivational inputs and the cognitive and motor components of action. These deficits are found to have great effects on living independently and psychosocial functioning (Delisa & Gans in Burns, 2008c:162; Uomoto & Uomoto, [sa]:1 & Struchen and Clark, 2007:22).

TBI can also lead to agitation and aggression and it is found to be part of the clinical picture of a person who is emerging from a coma (see Rancho Los Amigo levels of cognitive functioning). The frontal regions that are often injured in TBI are believed to play an important role in the inhibition of impulse and inappropriate responses. Many patients never fully regain control over volatile or disinhibited behaviours. This can present itself mildly as irritability or severe as outbursts of physical or verbal aggression (Burns, 2008c:162). While violent behaviour is rare, it can occur. Mostly, people will feel angered more easily and be more prone to verbal outbursts (Struchen & Clark, 2007:23).

According to Uomoto & Uomoto ([sa]:2) and Burns (2008c:162) more than half of patients involved in TBI rehabilitation suffer from depression or have at some point after the injury. The depression probably results from neurological and psychosocial factors. “The diffuse axonal injury of TBI induces acute disruption of neurotransmitter systems and it is theorised that neurotransmitter depletion, particularly in noradrenergic and serotonergic systems, could contribute to acute depressive systems” (Burns, 2008c:162). Struchen & Clark (2007:24) add that injury-related factors, including the location of the injury and neurochemical dysregulation, along with psychosocial factors, including pre-injury psychiatric history, high levels of perceived stress and poor coping skills are all thought to contribute. Apart from depression, emotional lability can also be present.

As stated previously, a lack of insight into limitations (including behavioural difficulties) make intervention difficult (Burns, 2008c:162). A lack of insight into limitations has been mentioned, but due to the great effect not only on TBI patients but also their family and caregivers, the researcher will provide more information. According to Burns (2008c:163) persons with TBI are usually less aware of cognitive and behavioural deficits than of physical deficits. Some may be aware of deficits but show poor understanding of the consequences. Uomoto & Uomoto ([sa]:2) also report that poor awareness of own deficits may be seen. This may lead to the person not benefiting from verbal feedback and not learning from mistakes so that he or she will end up repeating them. Webster, Daisley and King (1999:597) state that the family would like to have the TBI patient return to a previous level of functioning, especially in the early stages of rehabilitation. These may be due to differing perceptions of limitations and

lack of self-awareness in the person with a TBI. According to Kneipp(1991:169) “...the individual is exceedingly egocentric; the individual may persist in making demands on family members, without a word of thanks for their efforts” The researcher is of opinion that while family members might understand this in the acute rehabilitation phase, it might become more difficult in the long term to care for someone who doesn't seem to appreciate what you are doing.

It is the researcher's opinion that all of the above named limitations contributes to the complexity of TBI and the challenges that face family members and caregivers.

2.6.5 Assessment Scales and outcome measures

Subsequently the scales and outcome measures that are used to monitor the progress of TBI patients will be discussed.

2.6.5.1 The Glasgow Coma Scale (GCS)

“The Glasgow Coma Scale was created as a standardised clinical scale to facilitate the reliable inter-observer neurological assessments of head-injured patients who are in a coma” (Burns, 2008a:79). According to Khan *et al.* (2003:291), it generates a score between 3 and 15 based on a person's abilities in eye opening and motor and verbal functions. Presently it is used as a neurological scale to document the conscious state of a person. The value is mostly in using serial GCS scores as a predictor of outcome. A GCS score that remains low, or a high score that decreases, predicts poorer outcomes than a high score that remains high or a low score that progressively improves. The scale scores in the range of 3 to 15. Patients in a coma usually score between 3 and 8 (Burns, 2008a:79). Khan *et al.* (2003:291) states that it rather gives a prognosis for survival than for functional outcomes.

From her experience in working in a rehabilitation unit, the researcher is aware that the GCS is also used as admission criteria for acute rehabilitation. Usually patients with a GCS lower than 8 are not admitted to the unit as they are not able to participate in the full programme.

The Glasgow Coma Scale is one of the most widely used scales and assesses the following: “eye opening in response to a variety of stimuli, best motor response to pressure on the fingernail bed and to supraorbital pressure, and best verbal response (Scott & Dow, 1997:709). According to Mazaux and Richer (1998:436) the use of the Glasgow coma scale and epidemiological survey methods are used universally with regards to functional prognosis and allow for accurate classifications of patients as mild, moderate and severe.

2.6.5.2 The Rancho Los Amigos Scale

The Rancho Los Amigos Scale was designed as an easy, useful tool to classify cognitive functioning after a TBI. It is used in the acute phase and currently also as an outcome measure during acute rehabilitation and on discharge. The different levels (as stipulated below), describe the level of cognitive functioning as patients emerge from coma and are often used for treatment planning (Burns, 2008a:79).

A person with a brain injury may show any of different states of altered consciousness, depending on the severity of the injury. Coma and consciousness are best understood if viewed on a continuum from death (complete absence of consciousness) to complete consciousness. It should be understood that coma is not a stable state and the person can fluctuate spontaneously or as a result of stimuli along the continuum towards different levels of consciousness (Scott & Dow, 1997:709).

The Rancho Los Amigos Scale is used for assessing a patient’s level of consciousness or cognitive functioning. It describes levels of a comatose patient’s reaction to stimuli or the environment (Malkmus, Booth and Kodimer in Scott & Dow, 1997:709). Currently in the rehabilitation unit where the researcher used to work, the Rancho Los Amigos Scale is also used to explain behaviour to family members. It is found to be a great tool to ease family members’ concern about behaviour in the sense that for the level of cognitive functioning, it indicates what can be expected.

Level I - No response: total assistance

“Complete absence of observable change in behaviour when presented with visual, auditory, tactile, proprioceptive, vestibular or painful stimuli.”

Level II - Generalised response: total assistance

The person shows generalised reflex response to painful stimuli and responds to repeated auditory stimuli. The person responds to external stimuli with generalised physiological changes, gross body movement and/or non-purposeful vocalisation. All responses can be delayed.

Level III - Localised response: total assistance

The person withdraws or vocalises in response to painful stimuli and turns towards or away from auditory stimuli. Blinking occurs when a strong light is presented to the visual field and moving objects are sometimes followed. The person responds to discomfort by pulling on tubes and responds inconsistently to simple commands. Responses may be directly related to the type of stimulus. Responses may be limited to certain people only.

Level IV - Confused/agitated: maximal assistance

The person is alert and shows purposeful attempts to remove restraints. The person may perform activities such as sitting and walking but in the absence of purpose or on instruction. Short term memory is absent. Aggression and mood swings may be present. The person is unable to cooperate with treatment efforts and communication may be incoherent and inappropriate to activity and environment.

Level V - Confused, inappropriate non-agitated: maximal assistance

The person is alert but wandering. Agitation may be present when in an unstructured environment. The person is not orientated to person, time or place but can show sustained attention for short periods of time. The person may demonstrate inappropriate use of objects without external direction, but is unable to learn new information. Responses are often random and not goal directed in relation to instructions. Responses in social situations are often automated and only for brief periods when cues are provided. Confabulation is present in the absence of clear structure and direction.

Level VI - Confused, appropriate: moderate assistance

The person on level VI is inconsistently orientated to time, person and place. They are able to perform highly familiar tasks when moderate assistance is provided and there are no distractions. Memory is improving and the person is showing vague recognition of some staff. The person is becoming more aware of self, family and basic needs. Maximal assistance is needed to learn new information and there is little to no carry over. The person generally displays poor insight into impairments and safety risks.

Level VII - Automatic, appropriate: minimal assistance for daily living skills

Orientation has improved but moderate assistance is still required for orientation to time. The person is able to learn new information with minimal supervision and carry over is demonstrated. There is a superficial awareness of condition but the person continues to show poor insight. The person tends to be uncooperative, overestimates abilities, poor awareness of cause and effect and is unaware of others' needs and feelings.

Level VIII - Purposeful, appropriate: stand-by assistance

The person on this level of the scale is fully orientated and is able to recall daily schedules with memory aids. The person is able to learn new information and is able to initiate and complete familiar tasks. Awareness and acknowledgement of impairments is improving. The person is becoming more aware of others' wants and needs and can respond appropriately with minimal assistance. Depression, irritability, low frustration tolerance and self-centeredness can be present. Social interaction is improving.

Level IX - Purposeful, appropriate: stand-by assistance on request

Task completion has improved and uses assistive memory devices. Requires stand-by assistance to anticipate a problem before it occurs and to avoid it. The person is able to think about consequences of actions and can accurately estimate abilities. Depression, irritability and low frustration tolerance may continue.

Level X - Purposeful, appropriate: modified independent

The person is able to multi-task but may require periodic breaks. Social interaction has become consistently appropriate. Irritability and low frustration tolerance is now limited to when sick, tired or under emotional stress. Depression may still be present. The person is able to accurately estimate abilities and independently adjust to what the task demands.

(Rancho los..., n.d).

The researcher is of opinion that the Rancho Los Amigo Scale of Cognitive Functioning is a useful tool, especially for family members in understanding the specific behaviour their family member with a head injury is exhibiting according to the levels. It also shows progress through the levels with a clear description of behaviour that can easily be understood by family members and is not only filled with medical jargon.

2.6.5.3 International classification of functioning, disability and health

According to Burns (2008b:84) acute rehabilitation services holistically address three levels of incapacity by using interdisciplinary teams.

“These three levels (according to the World Health Organisation’s international classification of Functioning, Disability and Health) are:

- **Impairment:** *problems in body function (physiological and psychological function of body systems) or structure (anatomical parts of the body);*
- **Activity limitation:** *difficulties an individual may have in executing activities or tasks;*
- **Life participation restrictions:** *problems an individual may experience when trying to participate in life situations”.*

(Pasha & Pasha in Burns, 2008b:84)

According to the WHO (in Ross & Deverell, 2004:14) the international classification of functioning, disability and health (ICF), aims to provide a standardised framework for the description of human functioning and disability as a component of health. This includes alterations in functional state associated with health conditions on bodily, individual and societal levels. The information is organised to three levels:

- Bodily functions and structures
- Activity
- Participation

The ICF further distinguishes between environmental factors (from the individual’s immediate environment to general environment) and personal factors (age, race, gender, education, experience, personality, social background, coping style and so forth). These can either be seen as a facilitator or inhibitor (Ross & Deverell, 2004:14).

The researcher acknowledges the contribution by the ICF in holistically viewing patients with TBI. TBI patients cannot be fully understood without understanding their unique environmental and personal factors. This being said, it will only assist workers who have sufficient knowledge about ICF.

2.6.5.4 Functional independence and functional assessment measures

The functional independence measure (FIM) was developed as a tool to evaluate functional status and rehabilitation outcomes in different impairments, including neurological impairment after a TBI. The FIM consists of 18 items with a 7-point rating scale (1 indicates total dependence and 7 indicates total independence). This scale evaluates activities of daily living (ADL) - (self-care); bladder and bowel continence; mobility, communication, psychosocial adjustment and cognitive function. The FIM focuses more on physical aspects and less on social and cognitive deficits. The functional assessment measure (FAM) was developed to add 12 new items to the scale that include the evaluation of more complex cognitive, behavioural, emotional, communicative and psychosocial aspects (León-Carrión in Burns, 2008a:80).

Based on her experience, the researcher is of opinion that the FIM/FAM is insensitive for progress that is not of a functional independent nature. For example, at times very acute patients show improvement in a daily sitting routine but that it does not reflect on the FIM/FAM.

2.7 Rehabilitation

TBI rehabilitation is like all rehabilitation with the goal being to assist the person in achieving the highest level of return to their previous level of functioning. This is best managed by a specialised interdisciplinary team of professionals including a general practitioner, rehabilitation nurse, allied health professionals (physiotherapist, occupational therapist, speech therapist and social worker), neuropsychologist, and clinical psychologist (Khan *et al.*, 2003:291; 294).

According to Burns (2008c:160) during the last 10 years acute rehabilitation services for patients with TBI has rapidly expanded in South Africa. There has also been a growing awareness of problems associated with TBI and the need for structured therapy programmes, in order to achieve maximal functional outcomes. TBI research indicates that the highest rate of progress after a TBI will occur during the first six months after injury. There are different opinions with regards to the maximal duration of recovery. Some researchers believe that neurological recovery is practically complete by one year and others believe that it can continue for two years and more post injury. It is

clear, however, that certain areas, such as physical abilities and mobility recover more quickly than others,. Communication skills and higher level cognitive skills tend to take longer (Whyte, Hart, Laborde and Rosenthal, in Burns, 2008c:160). This was observed by the researcher in her work at an acute rehabilitation unit.

Rehabilitation does not aim to cure patients, but attempts to obtain maximal function following their injury. Where the level of pre-morbid functioning cannot be achieved, alternative compensatory strategies are taught. When the impairment is so severe and leads to permanent disability, the aim is to reduce the burden of care for others and to prevent secondary complications (Burns, 2008b:84). All seem to agree with the idea that functional independence, reintegration into the community and return to work are objectives for rehabilitation. But improving general well-being and improved quality of life of patients and their families is part of the ultimate goal for rehabilitation (Mazaux and Richer, 1998:436; Sander, Caroselli, High, Becker, Neese & Scheibel, 2002:649).

The researcher feels strongly that the period of rehabilitation should be utilised not only to restore functional independence or some level of it, but to prepare family members to not only take care of their brain-injured relative, but to mentally prepare and equip family members to do so. This is especially applicable to South Africa, as there are very limited supportive services available post rehabilitation. Many patients and their families also return to rural living, where support and assistance is not available.

According to Pulaski (1998:663), it is possible for patients with neurological dysfunction to improve their abilities through recovery of uninjured neurological tissue or through learning how to compensate for the lost function. The amount of recovery will depend on several factors, including the site of the lesion, size of the lesion, age and general health of the patient (Pulaski, 1998:663). Recovery of neurological function may be dependent on the brain's ability to use uninjured areas to assume function of the injured areas and the ability of uninjured brain neurons to grow new axonal branches and form new synapses with other intact neurons (Neistadt, 1994 as cited in Pulaski, 1998:663). Neistadt also points out that larger lesions may cause more damage and will have worse prognoses for recovery than smaller lesions. Older people or those with poorer overall health, have a poorer prognosis for recovery than younger, healthy adults.

The researcher has observed that patients with good support tend to respond better to rehabilitation. Families that have good and close family relationships also seem to be coping better in rehabilitation. Sander *et al.* (2002:654) support this view and state: “the results are consistent with clinical observations that patients who have supportive families do better in rehabilitation than those who do not”. According to Douglas and Spellacy in Webster, Daisley and King (1999:596), social support has been identified as the most important factor for family functioning when dealing with brain injury. The researcher has found that family members tend to rely on their faith and religion as a source of support in dealing with traumatic brain injury. Drenth (1991:51) states that religion plays a very important role in the South African culture and she views it as a system to be reckoned with in dealing with TBI patients and their families.

2.7.1 A rehabilitation unit

According to Hargrove and Derstine (2001:7) rehabilitation is:

a negentropic process that involves effort by the client, family, and health care provider. The clients are aided toward expanded freedom to mobilise resources on their own behalf. An optimal level of function is achieved through recognition of the uniqueness and wholeness of the individual.

Khan *et al.* (2003:290) state that rehabilitation is effective when using an interdisciplinary approach in close liaison with the patient, family and caregivers. Retraining of ADL's, pain management, cognitive and behavioural therapies and pharmacological management, are some of the issues that are dealt with in rehabilitation. The rehabilitation team commonly consists of

- patient and family;
- general practitioner;
- rehabilitation medicine physician (this member has not been present in the unit that the researcher worked at);
- rehabilitation nurse;
- allied health professionals: physiotherapist, occupational therapist, speech pathologist, social worker;
- neuropsychologist or clinical psychologist;
- vocational rehabilitation services (predominantly provided jointly by the occupational therapist and social worker); and

- other medical specialities: neurosurgeons and orthopaedic surgeons.
(Khan *et al.*, 2001:294).

Through her work in a South African rehabilitation unit the researcher gained valuable experience. She would like to share her experience of working at Life Eugene Marais Rehabilitation Unit.

In the unit where the researcher gained her clinical experience, acute inpatient rehabilitation is done. After patients are medically stabilised, they are usually admitted to the ICU (intensive care unit) and intubated if needed. Patients are not admitted to the rehabilitation unit prior to being extubated. This is mainly due to agreement with medical aids that patients will receive at least 3.5 hours of therapy per day and an intubated patient is still too acute and will find such a therapy programme too strenuous. Once a patient has been admitted to the rehabilitation ward, assessments by the interdisciplinary team follow within 24 hour of admission. The interdisciplinary team include the following team members: rehabilitation doctor, physiotherapist, occupational therapist, speech and language therapist, neuropsychologist or clinical psychologist, social worker, dietician and a member of the nursing team. An admissions report is sent to the funder (medical aid) within 72 hours of admission. Within the first week of admission, a family meeting is held with the family and all members of the interdisciplinary team, including the doctor, case manager and a representative of the nursing staff. The family meeting is usually chaired by the social worker and feedback about assessments is given to the patient and family. Goal setting for the period of rehabilitation is done during the family meeting. The family meeting also serves as a platform for the family to have their questions answered. A follow-up family meeting will only be held if felt necessary by the rehabilitation team or if requested by the family. Patients are included in a daily therapy programme with time slots for therapy, meals, rest and relaxation. Group activities are also presented. Once patients are well enough, caregiver training is started and patients are encouraged to go home for weekend leave of absence. This occurs first for a day at home, then a sleepover at home and later for a full weekend at home if all is going well. Through the process, it is the role of the social worker to prepare, assist and support family members and patients. The role of the social worker in a rehabilitation unit will subsequently be discussed.

2.7.2 Role of the social worker

Berkman (in Leukefeld & Battjes, 1989:153) identifies five selected objectives for social work role in the multidisciplinary team, namely to

- assess the psychosocial and environmental stresses that physically ill persons and their families may encounter and to provide direct therapeutic help;
- assist patients and families in optimum use of social-health care programs;
- make appropriate social health care and prevention programs available and accessible to all patients in need; and
- contribute to comprehensive treatment of the patient by collaborating with the physician and other personnel involved.

According to Heiss (in O'Toole 2001:41) the focus of social workers in a rehabilitation setting is on psychosocial problems of patients and their families, including interactions among families, groups, organisations and communities. The social worker further contributes to the rehabilitation team with her knowledge of social welfare policies and federal policies and entitlements. Social workers provide support by assisting with long-term living arrangements and referrals to coordinating agencies. Social workers are also involved in client and family counselling. Often, support groups are run by social workers (O'Toole, 2001:41). Cohn, (1998:793) states that social workers assist patients, families or other important people in the patients' life to achieve a maximal level of social and emotional functioning. Cowles (2000:110) states that the main role of social workers in health care is to provide clients with counselling and linkage to community services. In a rehabilitation setting, the researcher would have to agree with King (2000:74) that the social worker forms an invaluable link in the health team and the value of her or his contribution is immense.

Struchen and Clark (2007:28) contributes by stating that the role of a social worker in working with clients with TBI can be quite varied depending on the setting and the structure of the particular healthcare system in which the social worker finds himself or herself. Some of the various roles that social workers are likely to fill include, but are not limited to

- patient/client advocate;

- liaison between clinical/rehabilitation team and family;
- reference for resources;
- counsellor for patient and/or family or support system;
- discharge planner;
- public policy advocate; and
- facilitator for patient/family to become aware of and apply for sources of financial or social assistance.

(Struchen and Clark, 2007:28).

In addition to the above-mentioned, the researcher would like to add and highlight the following:

- Educator for patient and family regarding diagnosis and implication of diagnosis;
- Facilitator for arranging family meetings and contact with other members of the multidisciplinary team as needed; and
- Liaison between patient/family and nursing staff to ensure that all needs of the patient are met and complaints are handled.

More specific tasks of the social worker will subsequently be discussed.

During the initial stages of TBI and hospitalisation in ICU, the role of the social worker is more centred on the family due to the nature of the injuries to the patient and may entail the following:

- Crisis management; supporting the family as they were not prepared for the admission;
- Handling of emotions with regards to the uncertainty of the prognosis, sadness and anxiety;
- Emotional support with assessment of the families' current coping mechanisms;
- Preparation of long hospitalisation and rehabilitation ahead;
- Practical assistance, i.e. accommodation;
- Assessment in terms of family roles, relationships, reactions and resources; and
- Bereavement counselling if needed

(Germain and Hubschman in Drenth, 1991:64).

Drenth (1991:65) also states that families tend to listen selectively during the critical ICU stage and information needs to be repeated. The researcher has personally experienced this but would like to add that this was found not only during the critical intensive care (IC) stage but extends through the rehabilitation phase.

The researcher agrees with the above but has found through her clinical experience that most family members have not had any contact with a social worker during the phase directly after the admission into the intensive care unit.

After the initial critical stage and when the patient is medically stable he or she will be transferred to an acute rehabilitation unit. According to Drenth (1991:68), the role of the social worker in this stage is an extension of what it was during the critical IC period. The initial critical period has passed, but the family has to be prepared for the future and the reality of the situation.

The social worker plays an important role in the area of discharge planning. Developing a discharge plan that will ensure the safety of the patient and the prevention of delays in the discharge is the responsibility of the social worker. That being said, the role of the social worker starts from the day of admission until the day of discharge (Drenth, 1991:61). The researcher has found through her clinical experience, that discharge planning is an ongoing, at times complicated process that starts at admission and is not completed until the day of discharge. There are many factors that have to be taken into consideration when planning for patients' discharge, including family and environmental resources, cultural background, financial resources and so forth. All aspects that have an effect on the patient and his family should be taken into consideration when dealing with TBI patients and their families (Drenth, 1991:61). During this period individual counselling sessions and group work with members of family may be needed to address implications of a head injury, behaviour towards the person with a head injury and behavioural patterns. During this time the social worker should also be aware of the development of new crises. The development of insight in this matter is very important (Drenth, 1991:69).

The researcher agrees with this author, and feels that it is a good description of the role of the social worker in an acute rehabilitation unit. The researcher would just like to add

the arranging of caregivers, ample caregiver training opportunities and ensuring feedback after weekend leave of absence in preparation for discharge.

During this time, individual and group work, if suitable, with the TBI patient can also be valuable in addressing issues such as

- self- image;
- sexuality;
- peer group relationships;
- family relationships;
- role changes;
- finances;
- work opportunities; and
- hobbies.

(Steyn in Drenth, 1991:70).

The researcher would like to add that in the private sector, many patients with a mild to severe head injury will be discharged from rehabilitation prior to them being at a point in their rehabilitation where the above issues can be addressed. These issues will then have to be addressed post rehabilitation, on an out-patient basis. Due to the long term therapy programme, many patients will not have the financial resources to seek any private social work intervention. There are also very limited referral resources for people with traumatic brain injuries, especially outside of Johannesburg and Pretoria.

2.8 The reaction of the family to TBI

The family play an important role in the physical, cognitive and vocational rehabilitation of the person with a TBI (Brooks, Kozloff, Prigatano and Camplair, Kreutzer and Doherty in Kreutzer, Gervasio and Camplair, 1994:197). According to Uomoto & Uomoto, ([sa]:1) the family of the brain-injured person has to cope, manage and endure stresses and burdens during the recovery. Rehabilitation, adjustment to the changed person and maximising the potential of the TBI patient is often left to family members. Kreutzer *et al.* (1994:197) continue to state that the long recovery process, changed personality and altered abilities of the brain-injured person can be particularly difficult for the family and caregivers. It is also time-consuming and leaves little time to

maintain vocational or household responsibilities. Families are largely on their own, intensifying their difficulty in accepting the permanence and irreversibility of head injury (Williams, 1991:91). The researcher has found through experience, that during the process of rehabilitation, there seems to be adequate support from professionals and others, but as time goes by, it is the family that has to cope with the residual disability.

According to Williams (1991:87), when a family is informed about a loved ones' head injury accident, family members rush to the hospital playing out the worse possible outcome in their minds. When they arrive, the uncertainty regarding life and death may last for days or weeks. They maintain a vigil at the hospital and might have had no previous experience with tragedy. The family therefore hopes for survival, they just want the person to live. The immediate crisis that a family experiences after learning of their family members' TBI has a profound and lasting effect. The immediate reaction is a combination of disbelief that the injury has occurred, shock that the situation is so critical, anger that it has happened and feelings of guilt and fear about the future. After these intense emotions, families must react to events, but they have little opportunity to plan for the future on the information that they receive. These feelings of pain and fear sets the stage for the future where there will still be many situations where the family has to make critical decisions in the process of supporting their family member with a TBI. The initial delivery of information by professionals and how families translate it into their own reality can have a lasting effect on them. Williams continues by stating that while staying with the injured during this acute period, families remain in this state of loss reaction. The family focus has shifted completely to the person with the head injury and while events are changing daily, the family remains in a constant state of differing emotions. Each piece of news brings on a different reaction. It is during this time that families are most vulnerable and may rely on denial as a coping mechanism (Romano in Williams, 1991:89). At this point they do not always realise the extent of the problem and this allows them to mobilise their own emotional energy to face the future. The researcher has found through experience that during this stage, family members are unable to process new information, and all information has to be repeated on a regular basis. The researcher is of opinion that this is a good explanation of what family members experience during the initial acute phases.

Brain injury has a great impact on the family system and places a particularly high demand on the emotional resources of family members. There are countless emotions and impacts on the patient and family in the process of adjustment (Uomoto & Uomoto, [sa]:5). According to Williams (1991:89) a family usually has established relationships and roles, and being immersed in a medical setting in effect forces a family to “speak a different language”. In addition, all pre-existing relationships have to be re-evaluated as they have to request assistance and allow for flexibility. At times formed relationships cannot be restored and new relationships have to be formed. The author continues to state that after the initial crisis, there is not clear cut indication as to when the crisis is over, as it becomes redefined by the anxiety about the uncertainty about the future, guilt and the conviction of society that when a person becomes sick, he or she will be cured and sent home. The family is transformed to live in constant anticipation of a new crisis, and this becomes their way of life.

Emotional changes after a TBI may mean that family members may react differently to the person. This may include choosing words carefully so as not to provoke the person with a TBI and over time this can create a changed atmosphere in a family. “Over a prolonged period of time of walking on eggshells, family members may become weary and lose their patience with the survivor, which may in turn make the survivor more prone to anger outbursts” (Uomoto & Uomoto, [sa]:5).

According to Patterson and Staton (2009:149), many TBI patients seek counselling after hospitalisation and rehabilitation. This is either to assist with readjustment to life after the injury or for other mental health issues. Experiencing a brain injury and dealing with physical and neurological effects, creates a boundary experience that leads to patients dealing with the givens of freedom, death, isolation and meaninglessness (Yalom in Patter & Staton, 2009:150). It is the researcher’s opinion that in South Africa very few patients and their families seek counselling after hospitalisation and rehabilitation. This is based on feedback from the post-discharge telephonic follow-up service of Eugene Marais Hospital’s Rehabilitation Unit. This is mainly due to restricted financial resources.

Family members experience considerable changes in their quality of life following a TBI of a family member. Most report good support from the team and from friends, but

family members tend to feel lost, lonely and in full charge of their relative with a TBI (Mazaux & Richer, 1998:440). The study of Man (2002:1033) showed that families adopted different strategies for empowering themselves throughout their individual coping process. It was also found that family members were subjected to high levels of stress. They were so involved in the caring process, that they neglected themselves. Their feelings also seem to fluctuate between feeling upset that their family member has to live with a variety of disabilities, to being worn out and frustrated by the demands of caring for him or her. According to Uomoto and Uomoto, ([sa]:4) a dysfunctional reaction to the situation with a family member with TBI is to overcompensate for the decreased functioning of the person and by making him or her the centre of family life, inviting other members into a lifestyle which does not accommodate their own needs and goals.

Another huge impact on the family is social isolation. Social isolation may be caused by others' avoidance of the disability, but may also be due to the person with a TBI's difficulty to maintain and build meaningful relationships (Tate, Lulham and Broe in Webster *et al.*, 1999:596).

It is clear that family reactions following the onset of brain injury resemble the psychological reactions to trauma and bereavement (Man, 2002:1032; Painter, 1990:70). Family reactions to TBI include "severe anxiety, denial, anger, withdrawal from other family members, poor decision making skills, rigidity, low frustration tolerance and guilt" (Johnson & Higgings, Roger and Kreutzer, Zegeer in Painter, 1990:70). According to Lewis & Rosenblum (in Ross & Deverell, 2004:36), disabling conditions can lead to strong emotional reactions in the affected person, as well as in others in the environment. These reactions tend to be applicable across the broad spectrum of disabilities and chronic conditions and are often a manifestation of grieving. The stages of the grieving process by Elizabeth Kübler-Ross (in Ross & Deverell, 2004:36), is applicable to the grieving process, after a disabling condition such as a traumatic brain injury. The different stages are

- shock, numbness and disbelief;
- relief;
- denial;

- bargaining;
- guilt;
- depression;
- anger;
- anxiety and
- acceptance and coping.

People can oscillate between hope and despair, anger and denial, and specific life crises can again plunge one into an emotional state which one has already successfully negotiated in the past. Moreover, acceptance is not necessarily inevitable, some people never reach this stage (Ross & Deverell, 2004:36).

There is some critique for using these stages for a TBI patient such as that it oversimplifies the complex processes that the people go through. They were particularly concerned about the expectation that people should accept the injury and felt that one could not mourn and accept the disappearance of someone who has not died, especially one who may still present with disruptive behaviour (Kay & Cavallo, 1991:136). While the researcher can understand this viewpoint, she has found it useful to put families at ease by explaining that what they are feeling can be expected for what they are going through.

The stress Marcelissen (in Williams, 1991:92) described can be exemplified by eight situations that generally contribute to stress experienced by families post head injury. They are not in any specific order and often overlap. Each stressor increases the frequency and intensity of reactions to loss.

- Cognitive and social problems
Lezak (in Williams, 1991:92) state that studies have indicated that cognitive and social problems cause more stress on family members than physical problems.
- Lack of information
During the acute phase families do not receive the information that they need to make long term plans. As a result, they are not adequately prepared to manage problems as they arise.
- Lack of services
Families of TBI patients do not always have information about their options and choices and services may be restricted because of geographical location. The

researcher would like to add that in her experience, most TBI patients and their families have no access to any services after discharge from rehabilitation.

- **Uncertainty of the future**
Rapid progress early in the process may create expectations for prolonged steady progress.
- **Finances**
Short- and long-term financial issues are reported to be of major concern to the majority of families (Jacobs in Williams, 1991:94). Costs are direct as well as indirect including loss of income, interference with career advancement, and travel expenses.
- **Role changes**
The family may have found ways to cope while the person was in rehabilitation, and may find it difficult to give up these new roles. The person with the TBI may also find it difficult to cope with his or her new role. The role changes affect each family member and the way they relate to each other. As a result, family functions are affected (Kneipp, 1991:167).
- **Social isolation**
In the early stages after the injury, family and friends may still visit often and give abundant support, but as time passes, people may withdraw their support (Bond in Williams, 1991:95). People move on, not knowing how to include the person with a TBI in their lives. This results in the person with a TBI heavily relying on his or her family.
- **Prolonged caretaking**
Many people do not have relief or even a temporary respite from the demands of taking care of a brain-injured family member.

The researcher would like to agree with all of the above named stressors. It will be important for the social worker working in the acute phase to keep these in mind, in order to prepare the family for the future and to ensure that they have good coping strategies to deal with the stressful times ahead.

2.8.1 Caregiver/family needs

Johnson (1995:113) completed a phenomenological study on one family's experience with head injury. The author states that three themes captured the essence of the experience:

- helplessness and the need to hope
- the need to be informed and involved
- the impact of intubation/extubation

The study of Sigurgeirsdottir and Halldorsdottir (2007:390) identified six clusters of needs:

- *to be able to cope*
Participants felt that their ability to cope was strongly tied to their own personal traits and past experiences and preconceptions (Sigurgeirsdottir and Halldorsdottir, 2007:387-388);
- *to adapt to new characteristics of life and self*
Participants stated that they first had to accept that they were ill or were a patient and thereafter adapt to a new self. They also viewed rehabilitation as a phase on the way to better health (Sigurgeirsdottir and Halldorsdottir, 2007:388);
- *individualised caring*
Participants appreciated it when the staff took their individualistic needs into consideration and felt it was important that they be listened to by professionals with whom they had a caring relationship, based on mutual acceptance (Sigurgeirsdottir and Halldorsdottir, 2007:388);
- *emotional support*
All participants agreed on the importance of emotional support. First family, then peers, friends and healthcare staff (Sigurgeirsdottir and Halldorsdottir, 2007:388);
- *a sense of security*
Participants reported having a need for stability in staff and environment (Sigurgeirsdottir and Halldorsdottir, 2007:389); and
- *goal-orientated and progressive care*

The setting of realistic and achievable goals was important for participants (Sigurgeirsdottir and Halldorsdottir, 2007:389). It must be stated however, that these authors' study was conducted not only with TBI patients, but across the wide range of rehabilitation.

According to DeJong, Batavia and Williams (in Sinnakaruppin & Williams, 2001:654) within the TBI population, most caregiving activities are performed by family members. As the victims tend to be young males, the task is performed mainly by mothers and wives (Sinnakaruppin & Williams, 2001:654).

According to the study of Mauss-Clumm and Ryan (in Sinnakaruppin & Williams, 2001:654) priority needs were identified as clear explanations of the patients' condition and discussion of a realistic prognosis. Stebbins and Leung (in Sinnakaruppin & Williams, 2001:658) advised that family needs expanded from mainly medical and professional support during the first 2-year period, to include community-based support, caregiver and family support, financial resources and health information at later stages. The researcher would like to add support from the TBI patients' employer. Through clinical experience in a rehabilitation unit, the researcher has found that a lot of families' financial problems and frustrations were linked to non-supportive employers.

Sinnakaruppin & Williams' (2001:670) study showed that there was a correlation between parents' emotional behavioural changes, as well as changes in the patient's quality of life and the need for information on the consequences of head-injury. Their study further indicated that most of their subjects have emphasised the need for information on the topic of TBI, its effects and techniques for adjusting to the changes. Many indicated a need for honesty from healthcare professionals. The majority of carers indicated that they needed some time for themselves and a hope for the future.

It must be said that the period of rehabilitation is extremely stressful for family members. They have a need to be informed of the truth without relinquishing all hope. On the other hand, predicting of prognosis in the early stages remains very difficult (Mazaux & Richer, 1998:437).

The rehabilitation team and especially social workers should remain vigilant about the needs of family members. It is the researcher's opinion that how these first weeks are dealt with can minimise the trauma and help the family adjust to their reality. Rehabilitation teams are often so focussed on the TBI patient and it is the social worker who should advocate on behalf of the family.

2.9 Summary

This chapter focussed on the conceptualisation of traumatic brain injuries including basic anatomy of the brain, mechanisms of injuries, assessment scales and outcome measures, rehabilitation and the emotional experience of the injury. It focussed particularly on the physical, cognitive and emotional/social and behavioural effects of TBI.

When one considers all the information provided in terms of traumatic brain injuries, the effects and the emotional journey, then it is evident that research and the knowledge base have come a long way. There are however still gaps in the research, especially regarding the experience of the family of a TBI patient in a South African context who undergoes rehabilitation in the private sector.

It is clear from the literature review that traumatic brain injury not only impacts on the individual with the injury, but has a profound impact on the family and significant others. TBI patients and their families face a lifetime journey of coping. As more and more patients are referred for inpatient rehabilitation, it is important that all rehabilitation personnel have a clear understanding about the challenges that lie ahead for each family in order to support and equip them with skills to deal with it. The following chapter focuses on the presentation of the research findings.

CHAPTER 3

RESEARCH METHODOLOGY, EMPIRICAL RESEARCH FINDINGS AND INTERPRETATION

3.1 Introduction

This chapter explores three aspects of the study: the methodology followed, a profile of the participants of the study, and the research findings emerging from interviews exploring the experience of family members of Traumatic Brain Injury (TBI) patients. The data from all the interviews with the participants were transcribed and analysed and the research findings will be presented by means of the themes and sub-themes that arose from the analysis of the data, substantiated with verbatim quotes from the interviews and literature. A summary of the research findings will appear at the end of the chapter.

The following goal was formulated:

To explore the experiences of adult family members of their traumatic brain-injured family member's post-acute rehabilitation.

In order to achieve this goal the following objectives were formulated:

- To conceptualise traumatic brain injuries (TBI), mechanisms of injury, signs and symptoms, effects of TBI, assessment tools and outcome measures, cognitive rehabilitation and management of long term complications
- To explore adult family members' experiences of their traumatic brain-injured family member post-acute rehabilitation
- To make recommendations for acute rehabilitation centres and for social workers in intervening with traumatic brain-injured patients' family members post-acute rehabilitation.

Therefore the following research question guided this study:

What were the experiences of adult family members of the post-acute rehabilitation of their family member with a traumatic brain injury (TBI)?

3.2 Research Methodology

3.2.1 Research approach

This study was a qualitative study. Henning, Van Rensburg and Smit (2004:31) describe qualitative research as a study that is mostly presented in words and that usually focuses on the meaning that can be derived from the words that present the data. Fouché and Delport (2005:74) state that qualitative research is focussed upon understanding the meaning that people attach to their everyday lives.

This study strived to understand the experience of family members of traumatic brain-injured patients, from the acute phase to post rehabilitation. It further focussed on the meaning that these persons attached to their everyday life and the data was presented in words according to the perspective of the family members as participants.

3.2.2 Type of research

The type of research for this study was applied research. Fouché and De Vos (2005:105) states that applied research strives to solve policy problems and assist workers in the management of certain problems. It is further stated that applied research is: “most often the scientific planning of induced change in a troublesome situation”.

This study tried to provide more insight into the experience of family members of persons with TBI not only during acute rehabilitation but also post rehabilitation. In gaining insight into the experiences of family members, service initiatives can be adapted to fulfil the needs of these family members. This study thus proposed to address this problem that is experienced in practice.

3.2.3 Research design and methods

3.2.3.1 Research design

Mouton (1996:175) defines the research design as the plan of the researcher, how the researcher plans to approach the research problem. In this qualitative study the researcher made use of case studies.

According to Creswell (as quoted by Fouché, 2005:272) “a case study can be regarded as an exploration or in-depth analysis of a bounded system (bounded by time and or place), or a single or multiple case, over a period of time”. Fouché (2005:272) also quoted Stake who argued that “the sole criterion for selecting cases for a case study should be the opportunity to learn.”

This study was a collective case study. According to Fouché (2005:272) collective case study expands the understanding of the researcher on a social issue or population being studied. “The interest in the individual case is secondary to the researcher’s interest in a group of cases. Cases are chosen so that comparisons can be made between cases and concepts and so that theories can be extended and validated.” In this study, the researcher tried to create an opportunity to learn about the experience of family members of traumatic brain-injured loved ones. (The experience of the individual was secondary to the researcher’s interest in the population. The researcher further tried to interpret her findings and make it public for the field of social work in health care and more specifically for social workers and other helping professions working in rehabilitation post TBI.) The researcher provides more information on how the design was applied, by focusing on the data collection methods and the analysing of the data, as discussed later.

3.2.3.2 Population, sample and sampling method

Population refers to individuals in the universe that hold specific characteristics according to Arkava & Lane (in Strydom, 2005a:193). The population for this study was all the family members of patients who underwent rehabilitation as a result of traumatic brain injury in the Life Eugene Marais Hospital, Pretoria, Gauteng.

Kerlinger (in Strydom, 2005a:193) defines sampling as the process whereby a part of a population or universe is taken to represent that universe or population. It is thus presumed that this sample is representative of the population. In this study the sample was chosen by means of non-probability purposive sampling. Non-probability sampling is defined as sampling done without randomisation (Strydom, 2005a:198). Gravetter and Forzano (in Strydom, 2005a:201) adds that in non-probability sampling “the odds of selecting a particular individual are not known because the researcher does not know the population size or the members of the population.”

In this study purposive sampling was used to choose participants who were family members and caregivers of TBI patients. Silverman (in Strydom & Delpont, 2005:328) states that purposive sampling is usually chosen because it “illustrates some feature or process that is of interest for a particular study.” Strydom and Delpont (2005:329) further state that this sampling technique entails the selection of participants with characteristics which will benefit the study. Clear criteria are important. For this study the criteria were as follows:

A family member of the participants must

- have suffered a traumatic brain injury;
- have undergone acute rehabilitation at Life Eugene Marais Hospital in the last four years;
- have completed rehabilitation, in other words it must be post discharge;
- live in the province of Gauteng; and
- be able to speak and understand English or Afrikaans, irrespective of their gender, race, religion, culture or age.

It was decided that eight to ten participants who are family members of eight different TBI patients will be selected for this study, or when a point of data saturation is reached. After conducting interviews with eight participants it was realised that data saturation had been reached and no further participants were included in the sample.

3.2.3.3 Data collection methods

Data was collected through qualitative one-to-one interviews. Seidman (in Greeff, 2005:286) states that the researcher will make use of an interview, as there is an interest in the participants' life stories. For the purpose of this study, a semi-structured interview was used (Greeff, 2005:296). Greeff adds that researchers use semi-structured interviews, "in order to gain a detailed picture of a participant's beliefs about, or perceptions or accounts of, a particular topic." Greeff (2005:296) further advises that this method improves flexibility in that the researcher is able to explore specific interesting possibilities and the participant is able to provide clearer details. The participant is seen as the expert on the subject and will be allowed to tell his or her story. The interviews for the purpose of this study took place in the office of the social worker at Life Eugene Marais Hospital, Pretoria or at the participant's home. The choice was given to the participants. Interviews held at the hospital were therefore private and confidential in the office and those held at the participant's home, privacy was ensured by conducting it in a private room. The interviews were conducted with close adult family members of TBI patients. The main literature study was conducted prior to the interviews in order to prepare the researcher before initiating the interviewing. It was important for the researcher to understand all terminology prior to entering into the process. All interviews were digitally and tape recorded, to ensure success.

The researcher had a set of compiled questions which is called an interview schedule. This was to guide the interview and not to dictate it (See annexure A for the interview schedule). The researcher drew up a letter of informed consent that explained the goal and process of the study, as well as confidentiality and anonymity. This was done to assist participants in making an informed decision. Participants were also given the opportunity to withdraw from the study at any time. The letter of informed consent forewarned the participants that the interviews would be tape recorded. They were also informed that the data would be stored at the Department of Social Work & Criminology, University of Pretoria for 15 years, as required for archival purposes. The researcher kept a copy of the signed letters of informed consent and provided participants with a copy.

3.2.3.4 Method of data analysis

Creswell (in De Vos, 2005:334) is of the opinion that the best way in which the process of data analysis and interpretation of the data can be presented is in a spiral form. The researcher worked in analytical circles rather than taking a linear approach. Herewith follows the process in which the data was interpreted:

- **Planning**

Creswell (in De Vos 2005:334) defines this part of the process as: “planning of data in a systematic manner that is appropriate to the setting, participants, or both, and that will facilitate analysis before data collection commences.” The researcher conducted a semi-structured interview by using an interview schedule and recorded the interviews digitally to enable her to complete a comprehensive transcription thereafter. The researcher sought consent from each participant and ensured that they gave consent on the grounds of having comprehensive information on the study. Field notes were taken during each interview. The interviews took place in the social worker’s office at Life Eugene Marais Rehabilitation Unit or at the participant’s home, if that was more convenient. All interviews were held post discharge. The tape recording of the interviews was done with the consent of the participants. Anonymity and confidentiality was maintained by referring to the participants as Participant A, B, and C in the research report.

- **Data collection and preliminary analyses**

Creswell (in De Vos 2005:335) states that data analysis in a qualitative study involves a twofold approach. This includes data analysis at the research site during data collection and data analysis after data collection, away from the site. For the researcher, this section entailed the physical completion of the interviews and the recording. After each interview, the researcher completed field notes. These included the interviewees’ attitudes, body language and other observations of the researcher. If necessary she changed and adapted her ideas to ensure that the richest possible data were collected.

- **Organisation and management of the data**

According to De Vos (2005:336) this is the first step in data analysis away from the site. Each interview was transcribed word for word. The researcher completed the transcriptions herself, so that she could become familiar with the data. The researcher kept an electronic copy of these transcriptions as well. The participants were referred to as participant A, B, C. Confidentiality was very important to the researcher and she always tried to ensure it. The data was studied in order to identify the gaps, which needed to be filled before commencement of analysis of the data.

- **Writing and reading of memos**

During this stage, all the notes and transcriptions must be read several times. This is necessary because the researcher needs to focus on the content of the interviews to assist her in identifying themes (De Vos, 2005:337). The researcher also continued the making of notes as she worked through the data to assist with identifying themes and sub-themes.

- **Generating categories, themes and patterns**

Creswell (in De Vos, 2005:338) states that: “classifying means taking the text or qualitative information apart and looking for categories, themes, or dimensions of information”. During this phase the researcher focussed on the transcriptions in order to identify possible themes, categories and patterns. The researcher looked at language, themes and belief systems that repeatedly cropped up. Main themes were identified and subthemes were identified for every main theme.

- **Coding of the data**

Marshall and Rossman (in De Vos, 2005:338) state that the generation of categories and themes is the tough intellectual part of analysis. After doing this, the researcher then applied a coding scheme to those categories and themes, and diligently and thoroughly marked passages in the data using the codes. Codes may take several forms: abbreviation of key words, coloured dots, and numbers – the choice will be that of the researcher. The data in this case was coded by using different colours. Every

theme and sub-theme was assigned a different colour. The researcher was aware that the scheme might change as the process continues.

- **Test of emergent understandings**

Marshall and Rossman (in De Vos, 2005:338) state that once categories and themes are well in progress, evaluation of the plausibility of these developing understandings and exploring them through the data need to start. The researcher then tested the identified themes in terms of their usability for the field and how relevant they were for the phenomena that were being studied.

- **Searching for alternative explanations**

Marshall and Rossman (in De Vos, 2005:339) state that categories and patterns need to be challenged. Alternative explanations should be sought. Literature control regarding the themes and sub-themes was completed in order to consider alternative explanations.

- **Representing, visualising (writing the report)**

De Vos (2005:334-339) suggests that the findings of the study are presented in an analytical and logical way in a written report. The findings were presented in written and table format using verbatim quotes from the interviews and these themes were substantiated with literature.

3.3 Trustworthiness

A number of strategies were used in this study to establish trustworthiness of the findings and will be outlined below.

Morse and Richards (in Strandberg 2009:283) and Lincoln and Guba (in De Vos, 2005:346) propose the following assumptions of the qualitative paradigm:

- **Credibility** - which is the investigation of the study. “An in-depth description showing the complexities of variables and interactions will be so embedded with data derived from the setting that it cannot help but be valid.” The researcher was well-prepared for interviewing in order to be able to obtain the richest data

from it. During the presentation of themes and sub-themes, the researcher provided the verbatim quotes in Afrikaans (the original language the interviews were conducted in) and provided a translation into English thereafter. This was important because the researcher believes that some of the meaning might be lost when only the translation is provided. Some emotions and descriptions are just too difficult to be translated without changing some of its meaning. All participants were given the option to refuse participation and to withdraw at any time, to ensure that only the most willing participants were included in the study. However, no participant chose to withdraw. Furthermore participants were ensured that there are no right or wrong answers and that the researcher only wanted to understand their experience. If the researcher was in any way uncertain of a response it was clarified.

- Applicable – entailed the transferability of the results. According to De Vos (2005:346) transferability is sometimes seen as a weakness of the qualitative approach. The researcher used data from multiple cases and informants to strengthen the study's usefulness for other settings. The researcher has further constantly referred back to the theoretical framework of data collection and analysis to guide the study. Having firm roots in the theory, the researcher believes that she would be able to honour transferability. The details of this study have been shared openly in this document, to enable another researcher to complete the same study in a different setting.
- Consistent – entailed the dependability of the results. The researcher felt that to expect that the social setting of rehabilitating patients should remain unchanged is unrealistic. She was however diligent in the conducting of the study to remain open to possible changes. Some participants indicated that they would like to be interviewed in their homes and not in the unit. These participants' wishes were honoured. So the only inconsistency was that some participants were interviewed in the unit and others were interviewed at home.
- Lincoln and Guba (in De Vos, 2005:346) explain each assumption and adds a fourth: conformability. This captures the traditional concept of objectivity. The researcher planned a detailed literature review not to evaluate herself, but to rely solely on the data and then to substantiate it with the literature.

The researcher completed a critical self-reflexion about her biases. The researcher thought a lot about her own perceptions and views regarding the field of study in order to identify her own biases. She has worked for a number of years in a rehabilitation setting, but has only had contact with people with traumatic brain injuries and their families during the short period of rehabilitation. There was usually no contact after rehabilitation, thus leaving the researcher without any understanding of the bigger picture of what families experience. She was aware of her own understanding of problems that could arise during rehabilitation and tried her best to not let that influence the process. This could be a result of having met or known the participants from working in the unit previously, as either a social worker or later as a therapy manager. This made the interviews difficult, as participants had the need for counselling about the difficulties they were experiencing and also wanted information or help to deal with troublesome situations. The researcher tried to stay focussed as a researcher, but found it difficult to deal with these expectations participants had of counselling, even though it was clearly spelt out prior to interview that the focus was for research purposes only. Researcher dealt with this during the debriefing of each participant after the interview and referred them to the current social worker at the unit if it was needed. The researcher used the process of negative case by entering into interviewing without any expectations what she will find. The researcher further used principles as outlined by Johnson (1997:286) namely:

- Theoretical validity – all quotations as translated from the original Afrikaans verbatim interview transcriptions, were substantiated by literature. This assisted the researcher to seek alternative explanations for behaviour and emotions. The researcher believes by relying on theory and literature it increased not only validity but helped the researcher to focus on the theory and not on her own assumptions;
- Extended fieldwork – The researcher spent a significant amount of time the past five years in the field of traumatic brain injuries studying research participants and their settings to gain a better understanding of the field. This assisted the theoretical explanations to become more detailed and intricate (Johnson, 1997: 286);

- Theory triangulation – many different sources of literature as well as experts and colleagues were consulted on the topic. This way certain feelings and experiences could be explained by theory;
- Peer review – consultation with colleagues on some of the aspects of the data was done in order to seek alternative explanations. All quotations included in the study have thus been carefully selected and thought over.

On the basis of the above explanations, the researcher feels confident that she was able to ensure trustworthiness and as explained tried her best to avoid researcher biases.

3.4 Pilot study

Strydom and Delpont (2005:331) highlight the importance of conducting a pilot study, whether the study is qualitative or quantitative in nature. “In qualitative research, the pilot study is informal and a few participants possessing the same characteristics as those of the main investigation can be involved in the study, merely to ascertain certain trends.” The pilot study was thus a small scale study of the bigger study, using four participants. It is described in detail in chapter one.

3.5 Ethical issues

Neuman (2000:90) states that ethical issues can be seen as concerns, dilemmas or conflicts. He further states that ethical issues define the correct way in which to conduct research. Ethical refers to what is legally right or what is morally the correct way of working.

3.5.1 Avoidance of harm

According to Strydom (2002:64) it is possible to do harm to a participant on a physical or emotional level. Participants were informed about the possible impact of the study prior to commencement of the study. The researcher tried not to act as therapist in this study, but to do debriefing, following completion of the interview. There was no need for further counselling following the interviews and no harm seems to have been done. The researcher did however invite the participants to contact her, should there be any

need after the interview, in order for a formal referral to be made to the psychologist or social worker at the rehabilitation unit.

3.5.2 Informed consent

Informed consent implies that all possible and proper information regarding the purpose of the study, the procedures to be followed, and possible advantages, disadvantages and dangers have been communicated to all possible participants of the study. The author focuses on the accuracy of the information provided in order for the potential participants to make a voluntary, well thought through decision regarding participation in the study (Strydom, 2002:65). Neuman (2000:96) states that this process can be made easier by drawing up a written permission document. For this study the researcher compiled a letter of informed consent that explained the goal and process of the study, as well as assuring confidentiality. This was done to assist participants in making an informed decision. The letter of informed consent was read to and discussed individually with the participants, although a few requested to read it themselves. It was signed by them voluntarily prior to commencing with the interviews. Participants were also given the opportunity to withdraw from the study at any point. The written document prepared the participants that the interviews would be recorded and their permission was required. They were also informed that the data would be stored for 15 years, as required by the university for archival purposes. The researcher kept the original signed letters of informed consent and provided participants with a copy.

3.5.3 Violation of privacy / anonymity / confidentiality

According to Strydom (2005b:61) privacy refers to personal privacy while confidentiality refers to the “handling of information in a confidential manner”. Confidentiality was ensured by the researcher watching over the information that was entrusted to her, in order to protect the right of the participant. Participants were assigned pseudonyms, for example participant A, and recordings and transcripts were only handled by the researcher. Care was taken to ensure that no other person had access to these recordings and transcripts. Strydom (2005b:62) states that anonymity means that no person, including the researcher should be able to identify any subject afterwards. Due

to the researcher performing the interviews herself, she was not able to secure anonymity. Participants were however anonymous to each other.

3.5.4 Actions and competence of researcher

Strydom (2002:69) states that the researcher is ethically obliged to ensure that he or she is competent and has the necessary skills to conduct the research. The researcher felt comfortable, that is competent, to conduct the interviews, being a social worker and conducting interviews on a daily basis. It was however realised that these interviews would only focus on understanding the emotions of participants and would not focus on the delivery of support services. As stated earlier, the researcher found this difficult at times, but was able to redirect herself. What also made it difficult was that the participants at times looked at the researcher for guidance when discussing the difficulties they were experiencing. The researcher completed a research project and mini-dissertation as part of her undergraduate studies and also attended and successfully completed a postgraduate module: Research Methodology (MWT 864). The researcher was also guided by her supervisor of the University of Pretoria. On this basis, she felt confident that she was competent to complete this research.

3.5.5 Release or publication of the findings

Strydom (in Strydom, 2002:71) states that the findings of a study must be presented to the public in written form, otherwise even a highly scientific study will be of little meaning and would not be considered as research. The researcher has presented the final research report as accurately as possible and took extra care to ensure that all sources are correctly referenced. The mini-dissertation will be made available in the University of Pretoria library and a copy will be provided to Life Rehabilitation. A manuscript with the researcher's supervisor as co-author will be submitted for publication to an accredited journal.

3.6 Presentation of the research findings

The research findings will be presented by first indicating the profile of the research participants and then a presentation of the themes and sub-themes, including literature control and verbatim quotes from the transcriptions. Where ... is indicated, it means

some of the information has been omitted, as it is not applicable for that particular theme or sub-theme. Where [], ccc and xxx is indicated, the researcher left out information, without changing the message of what was said, but to protect the anonymity of the participant. Any names have also been replaced by pseudonyms. Extra information such as emotional reactions has been added in brackets (x). The researcher tried as far as possible to provide a true reflection of the data from interviews.

3.6.1 Profile of research participants

Table 2: Profile of research participants

Relationship to person with TBI	Number of participants
Sibling	2 (25%)
Husband/ Wife	4 (50%)
Parent	2 (25%)
Total participants	8

As purposive sampling was utilised, these participants were selected on the basis of the above mentioned criteria. Data saturation was reached after interviewing eight selected participants. There was a clear repetition of themes and sub-themes through all of the interviews, and researcher noticed that two mothers and the two wives had more or less the same experiences.

Table 3: Family profiles of participants

Participant A	Participant A is the sibling and primary caregiver of the person with TBI. The family member with TBI is a single man who lived with his mother. He had no children. He was the sole breadwinner of his household. He was injured by a gunshot wound in a suicide attempt. After discharge from hospital he lived with his brother, Participant A and his family. Together with the TBI, this family member was also blind. He was also unable to eat and had to be fed through a PEG tube into his stomach. This person had a high burden of care, due to him not being able to perform most self-care
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	activities and not being bladder and bowel continent. Participant A had good family support within his own family throughout the process.
Participant B	Participant B is the wife and primary caregiver of her husband who sustained a traumatic brain injury in a motor vehicle accident. They have two children of which one was a seven-week old baby at the time of the accident. The husband had just left his job to start his own business and was working long hours. There are no clear details of what exactly happened in the accident, as there were no eye witnesses. Participant B has always worked, but her husband used to be the primary breadwinner. With the start of his own business he did not have any insurance or salary protection in place, which placed a very high financial burden on his wife, who had to take care of him, their two children and increase her working hours, without good support from family or friends.
Participant C	Participant C is the wife and primary caregiver of her husband who sustained a traumatic brain injury in a motor vehicle accident. This was his second TBI in the period of one year. This couple has one child, who was three weeks old at the time of the accident. The husband with the TBI worked full time prior to his accident, but the injuries left him without any income. The couple lost their home and most of their possessions. They did however have good support from their family and friends and they moved in with participant C's family, who assisted her in caring for her husband and child. Participant C's husband was left with great cognitive and behavioural effects of the TBI, which included severe anger outbursts, which made living with him very difficult. Participant C had great difficulty accepting what had happened, due to the fact that this was her husband's second traumatic brain injury in a year. They had just settled in after his first injury when the second accident happened.
Participant D	Participant D is the sibling and primary caregiver of the person with a TBI. This person with a TBI is a single woman who lived alone,

	<p>had no children and was financially independent. She sustained a TBI in a motor vehicle accident and was left with some physical, but predominantly cognitive and behavioural effects. After hospitalisation and rehabilitation, she was discharged into the care of her sister who lived with her partner and daughter. Participant D had to use all of her annual leave for a month after discharge to take care of her sister who was unable to stay home alone. Participant D had difficulty in caring for her sister financially and had very little support from other family members, only the emotional support of her daughter and partner. Later in the process however, her sister with a TBI went to stay with another sister in a neighbouring country. This was however difficult for this participant, as she always felt that she was not looked after well enough. The patient returned to stay with her until she was able to return to independent living. She now lives alone, but is still dependent on her sister for support and guidance.</p>
Participant E	<p>Participant E is the primary caregiver and mother of her son who sustained a traumatic brain injury in a motor vehicle accident. Prior to the accident he was working, but still living at home. He sustained a minor TBI, leaving him with some communication, cognitive and physical limitations. Participant E herself had a brain tumor removed a few years ago and understood some of the effects of a brain injury well. She reported good support from her husband, friends and other extended family members, but still found the responsibility of looking after a child with a TBI daunting.</p>
Participant F	<p>Participant F is the primary caregiver and mother of her son who sustained a traumatic brain injury in a motor vehicle accident. Prior to the accident he was fully independent, working and living alone. He is a single man without any children. After his injury he moved back home, because he was unable to live alone. During this time, he was also retrenched from his work. Participant F received good support from her husband, friends and church. She coped well after discharge.</p>

Participant G	Participant G is the primary caregiver and wife of her husband, who sustained a traumatic brain injury in a cycling accident. Prior to the accident he was self-employed and doing well financially. The effects of the injury left him unable to work. The couple has two young children. The effects of his TBI include severe anger outbursts and aggression, which made living with him extremely difficult. Participant G had good support from especially her parents, but found dealing with their relationship with friends difficult. She always worked and managed to keep her husband's business going, but with significantly less income.
Participant H	Participant H is the primary caregiver and husband of his wife who sustained a TBI in a motor vehicle accident. Prior to the accident she was fully independent and working full time. The couple have children that are still of school-going age. The effects of the TBI has left participant H's' wife with severe cognitive and behavioural difficulties, especially high levels of aggression. He had very little support from family and friends throughout the process, which made it very difficult for him. He is now the sole breadwinner of his family, as his wife is unable to return to work as a teacher. All of the responsibilities of child rearing are now his.

3.6.2 Presentation of themes and sub-themes

The presentation of the themes and sub-themes that were derived from the transcribed interviews will now be presented. Each theme and sub-theme will contain narrative accounts from the interviews, using direct quotes. The quotes will be in Afrikaans, as all of the interviews were conducted in Afrikaans. Each quote has been translated into English just below the original, which could create the impression of the quotes being excessively long and as a result the chapter is also longer. This is however important in order to capture the accuracy of each participant's experiences, which could be affected through translation. These themes will each be discussed and substantiated with literature.

The following themes and sub-themes were derived from the data:

Table 4: Themes and subthemes

<p>Theme one: Understanding of TBI</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Knowledge of TBI ❖ Bodily harm vs cognitive impairments ❖ Personal meaning of TBI
<p>Theme two: Period of hospitalisation</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Trauma ❖ Uncertainty ❖ Hope ❖ Feeling unreal ❖ Fear ❖ Powerlessness
<p>Theme three: Family members' emotional experience of TBI</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Feeling sorry for the person with TBI ❖ Emotionally draining ❖ Pressure to keep going ❖ Feeling alone ❖ Marital relationship ❖ Social isolation ❖ Role changes ❖ Self neglect
<p>Theme four: Period of rehabilitation</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Rehabilitation experience ❖ Most difficult about rehabilitation ❖ Feelings about discharge ❖ Needs not addressed by team
<p>Theme five: Period post discharge</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Very stressful, demanding, busy time ❖ Constant responsibility ❖ Feeling guilty ❖ Patience ❖ TBI person determines emotional state ❖ Financial implications
<p>Theme six: Support systems</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Family and friends ❖ Religion ❖ Professional emotional support ❖ Employer support
<p>Theme seven: Effects of TBI</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Memory ❖ Laziness ❖ Impatience ❖ Lack of insight ❖ Changed person ❖ Aggression/anger/rudeness ❖ Social immaturity ❖ Selfishness
<p>Theme eight:</p>	<p>Sub-themes:</p>

Future	❖ Responsibility ❖ Expectations
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3.6.2.1 Theme 1: Understanding of traumatic brain injury (TBI)

Theme one: <i>Understanding of TBI</i>	Sub-themes: ❖ Knowledge of TBI ❖ Bodily harm vs. cognitive impairments ❖ Personal meaning of TBI
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When dealing with a family member with a traumatic brain injury, it is important for people to have a clear understanding of what happened to their loved one and to understand the complexities of their injury. Family members of a person with a TBI will deal with a wide range of medical personnel who will often use medical jargon and they quickly learn some of the words, but lack understanding. During the period of rehabilitation, much time and effort are put in to educate family members on their loved ones' diagnosis.

- **Sub-theme 1.1: Knowledge of TBI**

The following quotes reflect participants' knowledge of traumatic brain injuries.

Participant A: *“OK, ‘n hoofbesering is ‘n ernstige besering. En uhm in so ‘n mate ne dat uh, hoe erger dit is uh, of lyk hoe erger is die hoofbeserings en hoe minder sien jy. Of kan ek vir jou so sê sien jy kans dat so ‘n persoon dit gaan maak. Jy kan regtig sien, dis ‘n geringe hoofbesering of daai is ‘n erge. Maar as jy ‘n gat in iemand se kop dwarsdeur sien en jy hou hom so en dit loop uit, dan is dit redelik ernstig. En dan weet ons ook dat so ‘n hoofbesering is net ‘n kwessie van tyd. Daar is nie werklik iets wat jy aan so ‘n hoofbesering kan doen nie. As dit ‘n klein snytjie is kan jy sien mens kan hierdie snytjie toe maak of so iets maar erge hoofbesering is erg.”* Translation: OkK a head injury is a serious injury. And uhm in such a way yes that uh, the more serious it is uh, or the more serious the head injury is, the less you see. Or I can put it this way, you see the possibility that the person will make it. You can really see, this is a mild head injury or that is a serious one. But if you see a hole through his head and if you hold him and it pours out, then it is relatively serious. There isn't really anything that you can do with a head injury. If it is a small cut, then you can close it or so, but a serious head injury is bad.

Participant B: *“Wat ek verstaan fisies onder my man s'n is dat hy was in die kar ongeluk en met die wat hy, wat sy kop basies oral in die kop in die kar was is dit nou basies die brein het nou maar heen en weer geskud en is daar nou maar van die weefsels wat seergekry het en het die aartjies en goed nou nie regtig kontak maak nie. Sekere dele van die brein werk met sekere dele van die liggaam en dis hoekom van die goed geaffekteer is.”* Translation: What I understand physically with my husbands' is that he was in a car accident and with this that he, that his head was basically everywhere in the car and it was shaken and that caused some of the tissue to be hurt

and the veins and stuff do not make proper contact anymore. Certain parts of the brain work with certain parts of the body and that is why stuff are affected.

Participant C: *“Dat hulle persoonlikhede heeltemal verander. Uhm, hy is ‘n ander mens. Daar, terwyl hy daar lê is daar of ‘n kans op oorlewing of niemand kan sê nie.”*

Translation: That their personalities change completely. He is a totally different person. There, while he is lying there, there is a chance on survival or nobody can tell you.

Participant D: *“Ons was by die hospitaal gewees wat vir ons verduidelik het wat hierdie breinbesering of hoofbesering was en hulle het vir ons ‘n papier gegee wat dit alles behels. Uhm, ek dink dit was ja dit is haar linkerkantste brein het seergekry. Sy het bloeding op die brein gehad en dit het hier geskeur in die brein toe het sy bloeding op die brein gehad... Oukei die linkerkantste brein het seergekry so dit het nou meer te doen met haar geheue.”* Translation: We were at the hospital where they explained what this brain injury or head injury was and they gave us a paper on what it entailed. Uhm, I think, yes it was her left side of the brain that got hurt. She had bleeding on the brain and it tore in the brain then she had bleeding on the brain...OK, the left side of the brain got hurt and that has more to do with her memory.

Participant E: *“Ok, ek verstaan onder ‘n hoofbesering, []. Hoofbesering is maar die brein het seer gekry, ‘n stampie gekry. Iewers is iets, asof daar iets, ‘n deeltjie wat nie lekker werk nie met jou loop of jou spraak, dit hang af wat seergekry het werk nie. Dis waaruit ‘n hoofbesering bestaan. Iets wat nie werk nie, ‘n deeltjie wat seergekry het, soos ‘n rofie.”* Translation: Ok, I understand under a head injury []. Head injury is the brain that got hurt, it received a bump. Somewhere it is as if something, a part that is not working properly with your walking, your speech, it depends on what got hurt and is not working. That is what a head injury consists of. Something that is not working, a small part that got hurt, like a scab.

Participant F: *“Wat ek verstaan van ‘n brein besering, uhm, is dat dit deur in die meeste gavage, ‘n brein besering sê vir my dis ‘n, ‘n ernstig, dis ‘n ernstige storie. Ok, hulle het vir ons gesê hy is in ‘n koma, maar nou koma wat ek verstaan het, dit is nie medikasie nie. Ek het gedink dit is, dit beteken dit kan mos maar van die breinbesering wees wat hy in ‘n koma is.”* Translation: What I understand of a brain injury, uhm, if that it through the most circumstances, ‘n brain injury tells me this is serious, it’s a serious story. Ok, they told us he is in a coma, but what I understood is that it isn’t medication. I thought it meant it can be from the head injury that he is in a coma.

Participant G: *“Dis iets waaraan jy nou nie eintlik gewoond is of wat ook al nie, ek meen dit was vir my, was dit absoluut nou nogal ‘n hele nuwe wêreld... Ek dink elke geval is dalk miskien ook nou maar uniek op sy, op sy eie manier, maar dit is maar absoluut, jy weet uhm, in my geval nou toevallig, is dit maar baie gedragsveranderinge... en uhm en baie goed wat nou nie meer dieselfde is nie... Ek dink met ‘n breinbesering, absoluut, is dit, soos hulle altyd maar vir my verduidelik ook; die dokters maar sê het, jy weet, elke brein is maar uniek. So daar’s nie regtig ‘n, hulle kan dit nie vir jou 100% sê: “Hoor hier, dít is die uiteinde” nie. Jy moet maar die termyn deurloop en kyk wat eindig dit op mee, ja.”* Translation: It’s something that you are not used to or whatever, I mean for me it was, it was absolutely a whole new world...I think maybe every case is unique on it’s own way, but is it absolutely, you know uhm, in my case coincidentally, there are many behavioural changes...and uhm many things that are not the same any more...I think with a head injury, absolutely, it is, like they always told me; the doctors told me you know that every brain is unique. So there is not really a, they cannot tell you a 100%: “Listen here, this is the end”. You have to walk through the period and see what you end up with, yes.

Participant H: *“Wel ek sien dit as ‘n hoofbesering is waar daar ‘n hou teen die kop was en seker bloeding op die brein was en dan sien ek dit nou maar as ‘n breinbesering.”* Translation: Well I see it as a head injury is where there has been a bump against the head and surely bleeding on the brain en then I see that as a brain injury.

Discussion of sub-theme 1.1

As can be seen from the responses from the participants in the above quotes, for some the meaning of a head injury seems to be purely theoretical and for others of a more personal nature. The researcher did not clarify the theoretical knowledge, as she thought a personal account of the participants’ experience might be more significant. According to Drenth (1991:65) families tend to listen selectively during the critical IC stage and information needs to be repeated. This might also contribute to why some family members are not focussed to provide a clear description of what their family members’ diagnosis entails. What families understand under a TBI, remains a highly individual matter. According to Williams (1991:90) during families’ interaction with professionals, they seem to be speaking a different language. Many family members pick up on this jargon and become good in speaking “the language”. This is necessary as families will be involved with professionals for years to come to receive the services they need. The researcher did not really experience this during interviewing, except for one participant.

- **Sub-theme 1.2: Bodily harm versus cognitive impairments**

Participant B: *“En toe hy uit rehab uit kom en hy kan homself was, hy kan homself aantrek, hy kan homself, jy’s verlig, maar dan soos die teenpunt kom ook van hoe hy is.”* Translation: When he came out of rehab and he can wash himself, he can dress himself, he can, you’re relieved but then as the opposite comes – also of how he is.

Participant E: *“Ek dink as ons so bekommerd oor die been is dan dink mens maar dit kan nog genees, maar kan die brein genees? Ek dink diep binne waar ons dit weg gebêre het, dit was ons grootste bekommernis, myne veral. Ek onthou my man ook, maar ons het dit weggebêre, ons wou nie daaraan dink nie en daaroor bekommerd wees nie. Ons wou eers worry oor die been, dat hy net eers kan loop. En dat hy net eers kan gesond word die wond. Dan sal die ander stelselmatig kom.”* Translation: I think when we were so worried about his leg, then I thought but it can still heal, but can the brain heal? I think deep down where we hid it, it was our biggest concern, mine especially. I remember my husbands’ as well, but we kept it hidden because we didn’t want to think about it and be worried about it. We wanted to worry about his leg first that he can walk. And that it can heal, the wound. Then the other things will systematically come.

Participant G: *“Ek dink nie mens besef, die, jy’t hierdie liggaamlike seer of siekte en nou sit jy met die brein. Liggaamlik is alles goed wat jy half kan regmaak. So die feit*

dat hy liggaamlik toe kan nou naderhand beweeg, dit was toe nou vir my goed, maar toe's dit soos 'n skok na die tyd om agter te kom, maar weet jy wat, liggaamlik speel net eintlik een rol. Persoonlikheid en, en, en die breinbesering en alles, jy weet, ek dink mens is eintlik oningelig oor hierdie goed. Translation: I don't think you realise, the, you have this bodily ache or illness and now you have the brain. Bodily, everything is good that you're able to fix. So the fact that he could move his body later on was good but then it was a shock afterwards to realise but you know what, the body only plays one part. Personality and, and, and the brain injury and everything you know, I think a person is actually uninformed on all these stuff.

Discussion of sub-theme 1.2

When one looks at the above three quotes, it appears that the participants experienced a wave of relief when their family member with a TBI woke up after being in a coma, but that relief quickly made way for different emotions when the reality of a brain injury had dawned on them. Once they started to realise that the injuries they could see (i.e. fractures and lacerations) have started to heal, they were left with even more serious injuries and implications of the head injury they could not see. Marcelissen (in Williams, 1991:92) described the stress that family members experience post discharge and state that cognitive and social problems generally contribute to stress experienced by family members post head injury. Lezak (in Williams, 1991:92) states that studies indicate that cognitive and social problems cause more stress on family members than physical problems. This can also increase the frequency and intensity of the reaction to loss. According to the US National Institutes of Health (in Khan *et al.*, 2003:291) it is the “complex neurobehavioral sequelae that produce the greatest disruption to quality of life. Cognitive and behavioural changes, difficulties maintaining personal relationships and coping with school and work are reported by survivors as more disabling than any residual physical deficits”. This is similar with what the participants said in terms of realising that the physical injuries that their family members sustained could still heal, but once they did, they realised that they are left with the residual head injury.

- **Sub-theme 1.3: Personal meaning of TBI**

Participant A: *“Dis baie moeilik hoor, dis nie 'n maklike ding nie.”* Translation: It's very difficult; it's not a easy thing.

Participant B: *“Dis 'n heeltemal verandering van jou lewe. En daar is maar aanpassings wat gemaak moet word.”* Translation: It's a complete change of your life. And there are adjustments that have to be made.

Participant C: *“My man so afhanklik van ander mense te sien. Dit was die ergste want hy was 'n baie onafhanklike mens en was afhanklik van almal en alles.”*

Translation: To see my husband so dependent on other people. It was the worst because he was such an independent person and was dependent on other people.

Participant D: *“Dis moeilik. Ek sê vir jou ons het vreeslik, ons was baie emosioneel.”*

Translation: It’s difficult. I’m telling you, we did a lot of, we were very emotional.

Participant E: *“Ek was baie geskok gewees en ek het dit vergelyk met my storie en ek weet mens kan nooit dieselfde, g’n mens kan nooit dieselfde vergelyk met beserings nie.”* Translation: I was very shocked and I compared it to my story and I know a person cannot be the same, no person can compare the same with injuries.

Participant G: *“Ja weet jy wat, dit is moeilik... dis, dis vir my ‘n baie ingewikkelde besering... daar’s geen ‘quick fix’ nie. So ja, dis maar baie geduld en baie tyd. ...dis baie erg, ek meen, weet, jy’s naderhand eintlik so moedeloos dat jy soos ek nou sê; partykeer dan wens jy “Weet jy wat? Sou dit nie maar beter gewees het as hy maar liewer in daai koma gebly het nie, jy weet?”* Translation: Yes, you know what, it’s difficult...it’s, for me it’s a very complicated injury...there’s no quick fix. So yes, it’s a lot of patience and a lot of time. ...it’s very bad, I mean, you know, eventually you’re actually so despondent that you, like I’m saying, at times you wish, you know what, wouldn’t it have been better if he stayed in the coma, you know?

Participant H: *“Sjoe, dis baie erg.”* Translation: Shucks, it’s very bad.

Discussion of sub-theme 1.3

It is clear from the quotes above that, in no uncertain terms, dealing with a family member that sustained a traumatic brain injury is not easy. According to Uomoto & Uomoto, ([sa]:1) the family of the brain-injured person has to cope, manage and endure stresses and burdens during the recovery. Again this sub-theme has a highly individual tone, and participants had different reasons for saying that they found it difficult. This sub-theme was short and was only meant to give a brief account of how family members experienced the process or parts of it. It will therefore not be discussed in great detail.

3.6.2.2 Theme 2 and sub-themes: Period of hospitalisation

<p>Theme two: Period of hospitalisation</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Trauma ❖ Uncertainty ❖ Hope ❖ Feeling unreal ❖ Fear and anxiety ❖ Powerlessness
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Family members’ introduction to the process of TBI started with the process of hospitalisation. It is a highly emotional time, characterised by trauma, uncertainty, powerlessness and fear. Family members try to find balance and against all odds – hope.

- **Sub-theme 2.1: Trauma**

Participant A: *“As iemand deur sy kop geskiet word dan bars altwee die oë uit. Die een val vorentoe en bars uit die kop uit. Die ander een sal dalk net vorentoe uitpop, maar altwee die balle val uit. Sy kop was helemal in ‘n verkeerde rigting, sy kop was plat vorentoe en aan die een kant gebuig. Met ander woorde daar baie baie breinskade of sal ek sê skedelbreuke. Ek het regtig gedink ek sal hom eers tot by die hospitaal kan bring, maar toe ek hom so omdraai toe val alles aan die kant uit. Toe draai ek hom om en toe val alles aan die anderkant uit. Toe het ek ‘n handoek gekry en hom net toegemaak en ons is hospitaal toe met hom net so...Toe het ek hom vasgehou. Familielede en broers moet dit nie wees nie. Dit raak jou verskriklik.”* Translation: When someone is shot in the head, then both eyes burst out. The one falls forward and bursts out of the head. The other one will perhaps just pop out forward, but both eye balls fall out. His head was completely in the wrong direction, his head was flat in front and bent to the one side. In other words, there was a lot of brain damage or shall I say skull fractures. I really thought I would be able to bring him to the hospital first but when I turned him over, everything fell out of the one side and when I turned him over again, it fell out on the other side. I took a towel, covered him, and took him to the hospital like that. It is not supposed to be family members and brothers. It touches you in a terrible way.

Participant B: *“O, ek was hysteries. Ek was hysteries en uhm op daai punt weet jy nie wat om te verwag nie. Want ek bedoel die mediese mense bel jou en sê hulle soek jou mediese besonderhede en jy weet nie regtig hoekom nie. Is dit nou maar net om hom te laat opcheck, is dit -. jy verwag dit nie. En die dag as hulle vir jou sê breinbesering dan is dit - jou hele lewe kom tot ‘n stilstand want wat beteken dit? Wat gaan word van jou van hier af.”* Translation: O, I was hysterical. I was hysterical and uhm at that stage you do not know what to expect. I mean the medical people phone you and say they want your medical information and you don’t really know why, Is it just to have him checked out – you don’t expect it. And the day when they tell you brain injury then it is – your whole life comes to a standstill because what does it mean? What will happen to me from here on?

Participant C: *“Sy kop was letterlik dikker as sy skouers geswel. Jy kon omtrent nie sy oë sien nie. Dis nou nog, uh ek kry nou nog nagmerries oor daai gesig wat ek gesien het van my man wat daar lê.”* Translation: His head was swollen thicker than his shoulders. You could barely see his eyes. It is still, I still have nightmares ... of my husband lying there.

Participant D: *“Toe ons haar nou eers sien daar in ICU en al hierdie pype en goeters wat sy kan mos nou eers die uhm die ventilasie pyp in die mond gehad, maar toe sê dokter hy gaan nou ‘n gat maak hierso. So toe jy nou eers al hierdie masjiene en goed sien het jy op daardie oomblik gedink jissie sy gaan dit nou regtig nie maak nie. Dit was ‘n baie emosionele storie, hoor. Ons het byvoorbeeld die een dag daar aangekom toe het hulle haar geskuif toe sien ek nie die bed nie en ek sien net hierdie bed staan leeg waar sy altyd gelê het... Translation: When we first saw her in ICU, and all these pipes and gadgets because she could only, uhm she had the ventilation pipe in the mouth, but then the doctor said he was going to make a hole here (showing to brain). So when you saw all these machines and stuff, at that point you really thought goodness, she’s really not going to make it. It was a very emotional story. We arrived there one day for instance, and they had moved her bed, and I couldn’t see the bed and I only saw this bed where she used to lie was empty...”*

Respondent E: “Sy gesig was geswel, sy kop was geswel. En ek vra net healtyd vir hulle, het die brein seergekry, het die brein seergekry, omdat die kop geswel was? Het die brein seergekry? Toe sê hulle vir my nee, seker maar wag eers vir die dokter om jou te kom sien, en jou als kan vertel in detail. Wil hulle miskien nie ‘n flop maak nie. Ek was bekommerd oor die kop. Ek weet dadelik vir breinbeserings...Ek weet nie, ek was, ek weet nie. Dit was asof ek daardie oomblik net in ‘n boks gehou is. Asof jy nie regtig aan jou gevoelens uiting kan gee nie. Asof jy net, als is geblok. Jy kan nie skree nie, jy kan nie dit nie, jy kan niks nie, als is basies asof dit geblok is. Jy kan nie uiting gee aan jou gevoelens nie.” Translation: His face was swollen, his head was swollen. And I kept on asking them, was his brain hurt, was his brain hurt because his head was so swollen. Was the brain hurt? They told me no, wait for the doctor to see you, and he can tell you everything in detail. Maybe they didn’t want to make a flop. I was worried about the head. I knew immediately for brain injuries. I don’t know, I was, I don’t know. It was as if I was held in a box for that moment. As if I couldn’t express my feelings. As if everything was blocked. You can’t scream, you can’t, you can’t do anything, everything is basically blocked. You can’t express your feelings.

Participant F: “Daar was geen reaksie nie, as ek met hom gepraat het, was nie ‘n ooglid wat beweeg het nie...En terwyl ek so besig is sien ek hier kom ‘n gesig en hierdie gesig begin so swel. Ek kyk so en besef heng hier is nou iets verskriklik verkeerd...En sy roep toe die suster en die suster sê ons moet uitgaan. En ek jaag toe al die mense uit die eenheid uit en sê ons moet buite gaan staan. Gewoonlik het hulle, maar OK ons het dit nog nie vantevore by ons dit gesien het nie. En ons het toe buite gaan staan en besef ja hier is nou ‘n lelike ding. En ons wag en ons wag en loop daar op en af en niemand kan vir jou niks sê nie want hulle maak nie daai deur oop nie. En jy besef dit oor jou kind, hulle het nou almal laat uitgaan oor jou kind. En ons het daar buite gestaan en dit was seker so driekwartuur, na ‘n uur se kant. Jy sien net hoe hardloop hulle in en uit.” Translation: There was no reaction, when I spoke to him he didn’t even move an eyelid...And while I was doing that, I saw his face started to swell. I looked and I realised, *gosh*, something terrible is wrong...And she called the sister and the sister told us to go out. I chased all the people out of the unit and said we must stand outside. Usually they did, but OK it had never happened to us before. We stood outside and realised this is an ugly thing. We waited and waited and walked up and down and nobody can tell you anything because they do not open that door. And you realised it’s because of your child, they let everybody out because of your child. We stood outside; it was probably forty-five minutes to an hour. You only saw how they run in and out.

Participant G: “Dr. Xxxx sê, jy weet wat, dit was vir hom baie eienaardig. Hy sê toe, na al die ondervinding wat hy in jare gehad het met hierdie tipe van besering, sê hy, toe hy hom so afhaal, het sy breins letterlik half so uitgepop, hy sê dit het in sy hande, hy’t so met dit eintlik in sy hande gesit. Soos wat hierdie brein eintlik heeltemal so, so uitgeval het, kan ek nou maar sê...So, ja, weet jy wat, en toe’t hulle nou maar net die, die uhm, daai gedeelte van die brein afgehaal en hy was vir ‘n maand sonder ‘n skedel aan daai kant van die brein dat die swelling nou kon sak en so aan. Ek dink, vir my, wat snaaks was, is weet, na die tyd het jy hom nou maar gaan besoek in die ICU en, uhm, jy kon nie met hom praat nie, hy was onmiddellik in ‘n koma. Jy weet, soveel mense sê, “Iemand wat in ‘n koma is; weet, praat met hulle, dis goed, hulle kan hoor en als.” In sy geval mag ek glad nie met hom gepraat het nie, want enige iets sou die, uhm, het sy onderbewussyn, jy weet, enigiets is daar wat hom ‘excited’ dan maak, dan was daar drukking op die brein gesit. So, jy mag ook glad nie aan hom gevat het nie. Jy moes nou maar eintlik basies daar staan. En daar is nou geen beweging, jy weet, jy

kan nie eers met hom praat of vat of niks nie.” Translation: Dr Xxx said it was strange to him. After all these years experience in dealing with these type of injuries, when he took it off (piece of the skull), his brain literally popped out, he said he had it in his hands. As this brain completely fell out, I can say...So yes, you know what, then they removed that part of the brain and he was without that part of the skull on that side of the brain for a month for the swelling to go down. I think, for me what was strange, afterwards you went to visit him in ICU and, uhm, you couldn't speak to him because he was in an immediate coma. You know, so many people say, “someone who is in a coma, knows, speak to them, they can hear everything”. In his case, I wasn't allowed to speak to him because anything would, uhm, excite his subconscious, which would put pressure on the brain. I was also not allowed to touch him. I was basically only allowed to stand there. There was no movement, you know, I wasn't allowed to speak to him or talk to him.

Participant H: *“Dit was vir ons 'n traumatiese ervaring om te sien. Veral daardie eerste - sy het healtyd gelê. Dan besef jy nie eintlik sy kan nie sit nie, sy kan nie loop nie...tot ons haar die eerste dag hier gesien het en ons haar die eerste keer in 'n rolstoel gesien het. En ons toe besef het joe. Nie eers haar nek is styf nie. Sy kon nie eers haar kop ophou nie, dit was vir ons baie erg. Ek dink wat vir my ook baie erg was is as jy hier kom dat sy so vreeslik deurmekaar was, weet sy uhm sy praat deurmekaar, sy herken nie mense nie...Na 'n sekere tyd het hulle gesê sy moet vir 'n naweek huis toe gaan. En ek onthou baie goed toe ons soontoe ry, ek weet nie of dit vrees vir die ongeluk was of wat nie het sy haar kop net teen die sitplek gesit en haar oë toegemaak en sy wou nie vreeslik praat nie en toe ons by die huis kom ook waar jy nou dink sy gaan bly wees en die honde was vreeslik bly om haar te sien het sy dadelik vir my gesê “gee die sambok net hierso”. Sy het die honde begin slaan. Sy is vreeslik lief vir die honde en as jy haar nou wil kwaad hê moet jy nou iets aan haar honde doen. En sy het hulle geslaan jy weet” Translation: It was a traumatic experience to see. Especially the first, she was always lying down. Then you don't really realise she's unable to sit, unable to walk. You don't realise it because she is in bed permanently...until we came here and saw her in a wheelchair for the first time. Then we realised Wow, even her neck is stiff. She couldn't even hold up her head, which was terrible. I think what was also bad for me was, when you came here was that she was so confused, know she uhm, what she said was confusing, she didn't recognise people...After a while they said she must go home for a weekend. And I remember well when we were driving there, I don't know if it was fear of the accident or what it was but she placed her head against the seat and closed her eyes and didn't want to talk much. When we got home, where you'd think she would be happy and the dogs were very happy to see her, she immediately asked me, “Give me the *sjambok*”. She began hitting the dogs. She loves the dogs, and if you want to make her angry, then you must mess with her dogs. And she hit them.*

Discussion of sub-theme 2.1

The researcher found that most of the participants commented on feeling traumatised after seeing their family member for the first time in ICU. Most patients were intubated and due to the traumatic nature of the injury, many had other injuries as well. This left participants scared of what was going to happen and for many there was the question of would the person live or die. According to Man (2002:1032) family members' initial

reactions following brain injury resembled typical psychological reactions to trauma and bereavement. These feelings left them feeling scared and unable to express what they were feeling. Some report going into a survival mode and were barely coping with the emotional stress and other tasks such as work, childcare and so forth. After the patient was stabilised, more trauma came when the cognitive effects of the injury were visible, such as that they were not recognised.

According to Williams (1991:87), the immediate crisis that a family experienced after learning of their family members' TBI has a profound and lasting effect. The immediate reaction is a combination of disbelief that the injury had occurred, shock that the situation was so critical, anger that it had happened and feelings of guilt and fear about the future. The initial delivery of information by professionals and how families translate it into their own reality can have a lasting effect on them. Williams continues by saying that during this acute period, families remain in this state of loss reaction. The family focus has shifted completely to the person with the head injury and events are changing daily, the family remain in a constant state of differing emotions. Each piece of news brings on a different reaction. The researcher found that these traumatic reactions to what had happened, extend well into the rehabilitation phase and even after discharge, when behaviour and reactions of the person with TBI still leave family members feeling sad and traumatised.

- **Sub-theme 2.2: Uncertainty**

Participant B: *“In ICU is hy nog ‘n siek persoon en jy weet dat... Jy weet nie wat om te verwag nie, gaan hy heeltemal herstel?...Ek is ‘n mens, alles word beplan, jy gaan more opstaan, jy gaan bad, jy gaan alles regkry vir werk, jy gaan werk toe gaan. As iets uit daai wentelbaan uitgaan dan skud dit my hele aarde, regtig. Dit is, dit vat maar aan ‘n mens om nie seker te wees waarheen ons gaan nie, waarmee ons besig is, maar ja. So ja die onsekerheid vat baie. Dis maar wat die meeste van die tyd maak dat ek gaan sit en sê waarnatoe nou?”* Translation: In ICU he is still a sick person and you know that... You don't know what to expect, will he recover fully?... I am a person, everything is planned, you will get up tomorrow, you will prepare everything for work, you're going to work. If something goes out of orbit, then my whole earth is moved, really. It is, it gets to me to not be sure where we're going, what we're doing, but yes. So yes, the uncertainty takes a lot. It causes me to sit and think, where to now?

Participant C: *“Daar, terwyl hy daar lê is daar of ‘n kans op oorlewing of niemand kan sê nie. Hulle fight daai ICU absoluut uur vir uur...Wat as? Omrede dit sy tweede breinbesering is, gaan hy die keer bykom? Hoe gaan hy wees die keer? Gaan hy ooit weer kan loop?”* Translation: While he is lying there, if there is a chance of survival or nobody can say. They absolutely fight ICU for hours on end...what if? Because it is his

second brain injury, will he come to this time? How will he be this time? Will he ever walk again?

Participant D: *“Daar was baie stories...het skedelbreuk en van die skedel het nou in die brein ingesteek. So jy verdink allerhande goed en jy dink sy gaan dit nie maak nie en jy verwag die ergste. Totdat ons toe daar gekom het en Dr. Xxx vir my die plate gewys het en gesê het hoor hier ek gaan nou dit en dit doen en toe is dit nou nie skedelbreuk nie, dit is net die bloeding op die brein en goed, jy weet. So toe het ek maar gesê gaan voort, maar ja jy skrik jouself morsdood as jy hoor van skedelbreuk of breinskade of wat ookal...So, jy het nou nie daardie stadium geweet gaan sy nou verlam wees of gaan sy nie. Almal was bang vir nekbeseerings en sulke tipe goed. Ja sy was drie maande uh toe is sy in ‘n koma... So toe het dit ‘n gereelde dinge geword, elke aand ‘n gebed gedoen en so het sy beter geword. Maar as jy buite by die hospitaal uitloop dan huil jy maar vir jou dood, want jy weet nie wat gebeur môre nie. So dit was ‘n hartseer storie. (Crying)... Jy jy weet nie wat om te verwag nie. Haar hare is afgeskeer, jy weet nie of sy nou ‘n koolkop gaan wees nie. Of sy ooit weer sal kan werk nie of sy ooit weer dieselfde gaan wees nie. Sjoue dis nogal moeilik.”*

Translation: There were so many stories...has a skull fracture and a piece of the skull penetrated the brain. So you think of all the scenarios and you think she’s not going to make it and you expect the worst. Until we arrived there and Dr. Xxx showed us the scans and said I’m going to do this and this and it wasn’t a skull fracture, it was bleeding on the brain, you know? So I then said to go ahead, but it is absolutely terrifying if you hear skull fracture or brain damage or whatever...At that stage you did not know if she would be paralysed or not. Everyone was concerned about neck injuries and that type of stuff. Yes she was in a coma for three months...It became a regular thing, every night we prayed for her and she recovered slowly. But when you walk out of the hospital then you cry because you don’t know what happens tomorrow. It was a very sad story. (Crying)...You don’t know what to expect. Her hair was shaved off, you don’t know if she would be a vegetable. Oh, it’s difficult.

Participant E: *“Ek was hartseer, jou kind - gaan hy reg wees hierna? Wat gaan jy - eers het ek gedink aan hoe gaan ek hom hanteer? Gaan ek hom kan hanteer? Gaan ek na hom kan kyk by die huis? As hy by die huis uitkom, ek glo hy gaan heeltemal herstel, maar gaan ek dit kan dis wat ek eers gedink het gaan ek dit kan hanteer gaan ek na hom kan kyk. Dit was seer gewees.”* Translation: I was sad, your child – will he be fine after this? What will you, first I wondered how will I handle him? Will I be able to handle him? Will I be able to care for him at home? When he comes home, I believe he will recover fully, but will I be able, that’s what I first thought, to handle, will I be able to look after him? It was painful.

Participant G: *“Ja, weet jy wat, daai, daai moet ek vir jou sê was, was maar ‘tough’ hoor ... die oomblik wat iemand vir jou sê; “Hoor hier, hierdie is nou ‘n breinbesering”, want alles lees jy oor hierdie brein-goed. So die eerste ding wat deur jou gedagte, of my gedagte gegaan het is, OK, weet jy wat, hy gaan nou óf nooit weer dieselfde wees nie, óf hy gaan nooit eintlik hier uitkom of wakker word nie en hy gaan dalk hier uitkom en net nooit weer huis toe kan gaan nie. Jy weet, hy gaan dalk, wat, wat is die graad van hierdie breinbesering...Weet, jy weet nou nie, weet, jy hoor al hierdie goed. En dit is nou half die” tricky” gedeelte kan ek nou maar sê; jou brein, jy weet. So niemand kan regtig in feite vir jou sê “Weet jy wat dis - ” en almal sê “Wag en kyk”. En wag is nie ‘n dag nie, dis nie ‘n week nie. Na ‘n maand – 7 weke – lê hy nog steeds in die koma en, ek meen, niemand kan regtig - jy moet nou maar jouself probeer uitmaak en maar hoop en bid vir die beste wat nou hier gaan uitkom...So jy kon, ek kon my nooit self voorberei, weet op daai stadium was dit tussen lewe en dood, weet jy moet jou maar*

voorberei dat enigiets kan nou...die ergste wees. En kom jy nou oor daai feit dat hulle vir my sê, “OK, jy’s nou uit die gevaar uit.”, dan begin jy bekommerd raak oor OK, maar wat is nou die uiteinde? Gaan hy...ek meen, jy’s so gewens iemand kon net vir jou sê: “Weet jy wat, dít is hoe dit gaan wees.” En dan het jy iets gehad om jouself voor te berei.” Translation: Yes, you know what, that, that I have to say was very tough... the minute someone tells you, listen this is a brain injury, then you read everything about brain injuries. So the first thing that goes through your mind, or that went through mine is OK, you know what, he’s either never going to be the same or he will never come out of this or wake up or he will come out of this but will never be able to come home. You know, maybe he will, what is the degree of this brain injury...You don’t know these things now, but you hear all these things. And that is the tricky part, I can tell you, the brain. So no-one can tell you “you know what it’s –”, everyone says wait and see. And waiting isn’t a day, not a week. After a month – 7 weeks - he is still in a coma and I mean no-one can really – you have to figure it out yourself and pray and hope for the best for what is to come out of this...So you could, I could never prepare myself, you know at some point it was between life and death, and you have to prepare yourself that anything can now...be the worse. And if you cross that, the fact that they tell me, “OK, he is now out of danger”, then you are worried about what is the end of this? Will he...I mean I so wished that someone could tell me, you know what this is how would be. Then I could prepare myself.

Participant H: *“Ja dit is ‘n baie moeilike tyd vir ‘n mens want jy weet nie ‘n hoe ‘n mate die mens gaan herstel nie. Ek het die dokters daar in Xxx waar die ongeluk gebeur het, was dit asof hulle gesê het, as jy vir hulle vra want my vrou was amper drie weke of so in ‘n koma, semi-koma...So hulle kon op daardie stadium regtig nie vir my sê of sy sal beter word as wat sy is soos wat sy daar lê nie. En jy weet die susters daar, eendag daar, ek sal nooit vergeet toe ek daar aankom nie sê hulle dr Xxx, die neurochirurg wil jou sien. En toe kom die volgende een, het jy al vir dr Xxx gesien? Uit die hele ding kan jy agter kom hierdie is nou nie goeie nuus nie, jy weet. En dis daai onsekerheid, dis verskriklik. En dan selfs hy dan ook wat nie vir jou kan sê op daai stadium kan sê gaan sy weer loop, gaan sy weer praat, gaan dit die toestand wees soos wat sy daar lê gaan dit die toestand wees waarin sy - so dit was vir ons baie moeilik. Ons het nie geweet in hoe ‘n mate sy gaan herstel nie.” Translation: Yes it was a very difficult time because you don’t know to what extent the person will recover. I asked the doctors there in Xxx where the accident happened, and it was as if they said, when you ask them because my wife was in a coma or semi-coma for three weeks...They couldn’t tell me at that stage if she would get better than what she is, lying there. And you know, the sisters there, one day, I will never forget when I arrived there, they told me Dr Xxx, the neurosurgeon wants to see me. And then the next one came, have you seen Dr. Xxx yet? From the whole thing I could gather this is not good news. It is that uncertainty, it is terrible. And even then, what he can’t tell you is will she be able to walk again, talk again, will she remain as she is now? It was very difficult. We did not know to what extent she would recover.*

Discussion of sub-theme 2.2

The researcher found that almost all of the participants commented on how difficult they found the early stages of intensive care, but mostly they struggled with the uncertainty. Apart from the fact that they were still traumatised and concerned if their family member would make it through the critical stages, they were unable to plan anything. Some

participants commented on feeling worried about the future, how would they be able to cope with a family member with a head injury, and would they be able to care for them at home. According to Williams (1991:87-89) after these intense emotions, families must react to events, but they have little opportunity to plan for the future on the information that they receive. After the initial crisis, there is no clearcut indication as to when the crisis would be over, as it becomes redefined by the anxiety about the uncertainty of the future, guilt and the common belief that when a person becomes sick, he or she is cured and sent home. The family is transformed to live in constant anticipation of a new crisis, and this becomes their way of life.

- **Sub-theme 2.3: Hope**

Participant A: *“Jy hoop maar op elke klein ou dingetjie. Toe ons sien hulle leer hom weer loop het ons so gewens hulle kan hom net leer dat hy dalk sy toilet kan gebruik dan gaan dit vir ons soveel makliker wees, jy weet. Jy sien dit gaan vir jou ‘n probleem vorentoe wees maar jy hoop maar op elke ou dingetjie. Dit het ons ook weer ‘n gap gegee om te dink jis daar is tog ‘n verbetering. Hy gaan dalk ‘n bietjie beter raak al sê die dokter wat.”* Translation: You place your hope on every little thing. When we saw they were teaching him to walk again, we so wished that they could teach him to use a toilet then it would be so much easier for us. You see it would be a problem in the future, but you still hope on every little thing. It also gave us a gap to think *goodness*, maybe there is improvement. Maybe he will recover, even though the doctor said he wouldn't.

Participant B: *“Ek het nie dadelik gesien dis ‘n breinbesering nie. Ek het gesien hy was ‘n bietjie geswel, maar mens dink maar aan allerhande ander dinge, en nie ‘n breinbesering nie. Vir my was hy olraait, hy was weer my man, hy gaan lewe. Min het ek geweet wat eintlik aangaan... Ander kere is daar lig, dan dink mens gee dit net ‘n jaar soos wat hulle sê en kyk dan.”* Translation: I didn't immediately see it was a brain injury. I saw that he was swollen, but you think of all things and not a brain injury. For me he was OK, he was my husband again, he was going to live. Little did I know what was going on...Other times there was light, then you think just give it a year like they said and then see.

Participant E: *“Dis asof jy heelyd sit en fokus op hom op sy vordering, sodra jy vordering sien dan asof daai titseltjie vordering jou geduld toesmeer, jou jou “grumpygeid” rustig maak. Net ‘n titseltjie vordering het ek klaar vir mense gesê daar is ‘n liggpunt, daar daars hoop. En dit het my geduldig gehou.”* Translation: It is as if you sit and focus on him and his progress, and the minute you see progress it covers your grumpiness and calms you. Just a little progress said there is light, there is hope. That kept me patient.

Participant G: *“Ek dink toe hy uit die koma uit begin kom het en toe hy nou naderhand bietjie begin beweeg het. Al wat ek vir jou, wat, wat, wat ek dink, wat, wat mens doen, en ek dink dis maar menslik; vir die kleinste dingetjie wat gebeur het, soos ‘n oog wat geknip het, né, het jy hierdie verskriklike moed gekry en gedink ek, Nee man, weet jy wat, dis nie so erg nie, né? Hy sal ‘fine’ wees. En as hy begin beweeg het, het jy gedink nee, weet jy wat, hy gaan fine wees.”* Translation: I think when he started to come out of the coma and started to move. All that I, what I think, what a person does,

and I think it is just human, the smallest thing that happened like a eye that blinked, you were encouraged and thought, you know what, it isn't as bad. He'll be fine. En when he started to move you thought, no you know what, he'll be fine.

Discussion of sub-theme 2.3:

As the literature showed above, family members become focussed on the person with the TBI and how she or he is doing. As the participants indicated in this sub-theme, family members became totally focussed on their progress and every little progress made, whether significant or not, gave them hope that the person would recover and be the person they once knew. According to Williams (1991:87), when a family is informed about a loved ones' accident or head injury, family members rush to the hospital playing out the worst possible outcome in their minds. When they arrive, the uncertainty regarding life and death may last for days or weeks. They maintain a vigil at the hospital and might have had no previous experience with tragedy. The family therefore hopes for survival, they just want the person to live. This establishes a good link with the last two sub-themes of uncertainty and hope. It seems that the participants clung to the prospects of hope while trying to balance the uncertainty that the critical stages in ICU brings. Williams (1991:89) states that by staying during this acute period, families remain in this state of loss reaction. The family focus has shifted completely to the person with the head injury and as events change daily the family remains in a constant state of fluctuating emotions. Each piece of news brings on a different reaction. It is during this time that families are most vulnerable and may rely on denial as a coping mechanism (Romano in Williams, 1991:89). At this point they do not always realise the extent of the problem and this allows them to mobilise their own emotional energy to face the future. Johnson (1995:113) adds to the sub-theme of hope, with a phenomenological study on one family's experience with head injury. One of the three themes that captured the essence of the experience is: helplessness and the need to hope. During the critical IC stages, most participants indicated the need to hope and the researcher drew the conclusion that this is the reason why the focus seemed to be on the relationship between progress and hope.

- **Sub-theme 2.4: Feeling unreal**

Participant A: *“Maar dis baie erg, ek wens dit vir niemand toe nie. Dis soos ‘n, ‘n ek weet nie hoe kan ek dit vir jou beskryf nie. Jy - dis soos ‘n nagmerrie wat nie einde kry nie. Weet so iets.”* Translation: It is terrible, I do not wish it on anyone. It is like, I don’t know how to describe it. You, it is like a nightmare that has no end. You know, something like that.

Participant B: *“Ons is al 6 maande van die ongeluk af en ek dink nie dit het al ooit by my ingedring dat dit is dalk wat die lewe gaan wees nie.”* Translation: It is six months after the accident and I don’t think the idea has dawned on me yet that this is how life is going to be.

Participant C: *“Weet jy, baie verward; omrede dit sy tweede ongeluk in ‘n jaar se tyd was, was dit baie verward. Dit was vreeslik, ek kon dit nie glo nie. En dit was vir my, ek kon nie funksioneer, weet dink dis werklikheid wat my nou slaan, dis regtig wat ek nou sien nie. Ek dink eers twee dae later het dit eers regtig by my ingesink dat my man in die hospitaal is.”* Translation: You know, very confused because it was his second accident in a year, very confused. It was terrible, I couldn’t believe it. For me it was, I couldn’t function, I think it was reality that dawned, that is what I am seeing now. Only two days later the reality that my husband was in hospital dawned.

Participant E: *“Ek het nie gevoelens gehad op daardie stadium nie. Ek was dood. Dis asof ek, ek was net dood. Ek kon niks dink nie, ek het niks geweet nie. En eers toe hy in die hospitaal, toe ek hom die eerste keer in die hospitaal sien, met die pype en goeters op, toe besef ek.”* Translation: I didn’t have any feelings at that stage. I was dead. It was as if I, I was just dead. I couldn’t think anything, I didn’t know anything. Only when he was in the hospital, and I saw him for the first time with the pipes and other things, then I realised.

Participant F: *“So het ons maar alles beginne optel toe hulle hom op die masjiene sit, en toe besef ons maar iets vertel toe vir ons hierdie ding is bietjie ernstig, maar ek’t nooit kon dink, in daardie stadium ek weet nie of ek dit nie wou glo nie, maar ek’t nooit geglo my kind gaan doodgaan nie...Soos ek vir jou sê, dis vir so asof dit is, of dit nie gebeur het nie, of dit nie met ons gebeur het nie, asof dit iemand anderste was.”* Translation: We started calculating everything when they put him on the machines, and then we realised, something told us, this thing is serious. I never thought, at that stage, or I just didn’t want to believe it, but I never thought my child would die...Like I told you, it was as if it didn’t happen, as if it didn’t happen to us, as if it was somebody else.

Participant G: *“Ek moet vir jou sê daar’t dit vir my gevoel of ek besig is met hierdie fliëk. Besig om hierdie ‘movie’ te maak. Want ek meen, sulke goed hoor of lees of sien jy net eintlik in fliëks. Ek meen, dis nie, die ‘reality’ van dit is eintlik so half, jy weet, jy hoor dit altyd en jy dink jis, dit moet bad wees of iets. Maar totdat dit jouself raak, jy weet, en dan dink jy, die goed was vir my, soos half, dit was vir my soos ‘n fliëk of ‘n droom – ek wag om wakker te word. Ja, en hy hou nie op nie. (Laughing.) Hy hou baie lank aan, jy word net nooit wakker nie.”* Translation: I must tell you, it felt like I was busy with a movie. Busy making this movie. I mean, you hear or read or see such things only in movies. I mean, it’s not, the reality of it is actually...you know, you hear it and you think, *gosh*, that must be bad. Until it happens to you, you know, and you think, for me it was, like a movie or a dream – I’m waiting to wake up. Yes, and it doesn’t stop. (Laughing). It goes on and on and you just never wake up.

Discussion of sub-theme 2.4

Almost all of the participants mentioned that the experience of a family member with TBI, especially the critical IC stages, is just so terrible that it feels like a nightmare, a bad dream. One participant mentions that it felt like she was in a movie. Whether a bad dream or a movie, it seems that the experience is something that does not feel real – something that is so terrible, that it does not feel real. According to Lewis & Rosenblum (in Ross & Deverell, 2004:36), disabling conditions can lead to strong emotional reactions in the affected person, as well as others in the environment. These reactions tend to be applicable across the broad spectrum of disabilities and chronic conditions and are often a manifestation of grieving. The stages of the grieving process described by Elizabeth Kübler-Ross (in Ross & Deverell, 2004:36), is applicable to the grieving process, after a disabling condition such as a traumatic brain injury. One of the stages is, shock, numbness and disbelief. These feelings of shock, numbness and disbelief are the closest the researcher could find in the literature that illustrates what the participants describe in this sub-theme. Williams (1991:87) adds to this by saying the immediate reaction is a combination of disbelief that the injury has occurred, shock that the situation is so critical, anger that it has happened and feelings of guilt and fear about the future.

- **Sub-theme 2.5: Fear and anxiety**

Participant A: *“Jy is bang as die foon lui in die nag. As iemand uhm nou nog as die foon lui dan dink jy vir ‘n sekonde jis dis alweer bad nuus. Jy weet dan en dis nou al ‘n jaar na die ongeluk.”* Translation: You are afraid in the night when the phone rings. Even now, when the phone rings, for a second, you think *gosh* its bad news again. You know and it’s a year after the accident.

Participant C: *“Hulle was baie reguit met my en op daardie stadium, ja dit was my man wat daar gelê het, maar ek het ‘n babatjie. Wat, wat as hy nou iets oorkom, wat sê ek vir my kind as sy eendag groot is.”* Translation: They were very honest with me and at that stage, yes, it was my husband lying there, but I have a baby. What, what if he doesn’t make it, what do I tell my child when she is all grown up?

Participant D: *“Ja op daai oomblik dink jy die bed staan leeg wat daar is nie meer iemand nie, maar toe het hulle haar isolasie kamer toe gestuur.”* Translation: Yes, at that point you think the bed is empty because there isn’t anyone left, but they had only sent her to the isolation room.

Participant E: *“Ek het my klaar gesien ja eerste plek grumpy ja. Hy gaan baie kort van humeur wees en hy gaan miskien amper soos ‘n, ek het dadelik gesien in my geestesoog hy gaan soos hierdie, hoe druk mens dit uit? Soos ‘n koolkop. Hy gaan nie meer vir homself kan dink nie, hy gaan soos ‘n kleintjie wees en sulke dinge. En ek weet ek is ‘n ongeduldige mens en ek was bang ek gaan dit nie kan hanteer nie. ‘n Ma is maar ‘n ma veral met jou kind en die mense om jou is jy maar meer sensitief. Ek het*

gedink ek sal dit nie kan hanteer nie, maar ek het net gebid en gevra vir krag van bo af. Translation: I already saw in the first place grumpy, yes. Hy will be very short-tempered and maybe, I imagined, how do I express myself? Like a vegetable. Hy will not be able to think for himself. Hy will be like a small child. I know I am an impatient person and I was afraid I would not be able to handle it. A mother is a mother and you are more sensitive with your children and the people around you. I thought I would not be able to handle it, but I prayed and asked for help.

Participant F: *“Uhm, wat ek kan onthou van daai tydperk is maar net die vrees. As jy om jou gekyk het en jy het die mense om jou gesien en jy hoor dit gaan slegter.”* Translation: Uhm what I can remember from that time is the fear. When you looked around you, you saw people and you hear things are deteriorating.

Discussion of sub-theme 2.5

Participants reported feelings of fear and anxiety but for a variety of reasons. Fear and anxiety could also be closely linked to uncertainty. Due to participants feeling so uncertain and not knowing what to expect, fear and anxiety moves in. Family reactions to TBI include “severe anxiety, denial, anger, withdrawal from other family members, poor decision-making skills, rigidity, low frustration tolerance and guilt” (Johnson & Higgings, Roger and Kreutzer, Zegeer in Painter, 1990:70). The immediate reaction is a combination of disbelief that the injury has occurred, shock that the situation is so critical, anger that it has happened and feelings of guilt and fear about the future. After these intense emotions, families must react to events, but they have little opportunity to plan for the future on the information that they receive. These feelings of pain and fear set the stage for the future, where there will still be many situations where the family has to make critical decisions in the process of supporting their family member with a TBI (Williams, 1991:87). The fear and anxiety experienced by participants, was not only due to what was happening to their family member in ICU, but also to their own fears about the future and their own ability to care for a possibly severely disabled person.

- **Sub-theme 2.6: Powerlessness**

Participant A: *“Jis, ek het amper mal geraak. Jy kan nie glo, jy weet jy’s verslae, jy’s magteloos. Jy weet daar is niks wat jy kan doen nie. Weet jy jy sou so graag iets wou doen, maar jy, jy voel, die magteloosheid wat jou storm op daardie stadium maak jou mal. Jy slaap nie weer daarna nie en jy weet dis moeilik om vir jou te sê... Ek kan dit nie vir jou beskryf nie. Dis iets wat ek nie my grootste vyand toewens nie – jou magteloosheid... Magteloosheid, is soos ‘n eensaamheid, jy kan dit nie vir iemand beskryf nie. Dis iets wat jy ervaar en dis moeilik.”* Translation: Gosh, I almost lost my head. You cannot believe it because you are astonished, you are powerless. You know there is nothing that you can do. You know, you would love to do something but you, you feel, the powerlessness overtakes you and it causes you to lose your head.

You can't sleep after that and it is difficult to say...I can't describe it. It is something that I wouldn't wish upon my biggest enemy – your powerlessness. Powerlessness is like loneliness, you can't describe it to someone. It is something that you experience and it is difficult.

Participant D: *“As ek daar kom en sy het my nie herken nie, het ek maar bietjie gesit, maar as ek nou te hartseer geraak het, het ek maar liewers gegaan.”* Translation: When I arrived there and she didn't recognise me, I sat for a while but if I became too sad I rather left.

Participant G: *“Ek meen dis maar soos met jou kinders en almal, as iemand in die hospitaal is wil jy tog 'n blommetjie vir hom vat, of jy wil tog, jy weet, bietjie omgee, of sy hand vashou...of wat ookal. In hierdie geval is dit so erg, jy kan nie...jy kan niks doen nie. Jy weet jy staan daar, jy weet nie eers of hy weet jy staan daar nie...jy weet nie of staan jy eintlik daar langs 'n lyk of dis 'n...jy weet nie eintlik of is daar lewe of dood nie...En, uhm, ja, so, ek moet sê daai, daai tyd was regtig baie erg.”* Translation: I mean it is like with your children and everyone, if someone is in the hospital you want to take them a flower or you want to, you know, care or hold his hand...or whatever. In this case it is so bad, you can't...you can't do anything. You know you're standing there, you don't even know if he knows you're standing there, you don't even know if you're standing next to a corpse...you don't really know if there's life or death. Uhm, yes I must say, that was really terrible.

Discussion of sub-theme 2.6

This sub-theme of powerlessness has been mentioned by three participants. People want to do something for a loved one when they are ill and when confronted with TBI the feeling of powerlessness is difficult. The powerlessness that the participants mentioned was confirmed by the study of Johnson (1995:113) on one family's experience with head injury. The author states that three themes captured the essence of the experience:

- helplessness and the need to hope;
- the need to be informed and involved
- the impact of intubation/extubation.

3.6.2.3 Theme 3 and sub-themes: Family members' emotional experience of TBI

<p>Theme three: Family members' emotional experience of TBI</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Feeling sorry for the person with TBI ❖ Emotionally draining ❖ Pressure to keep going ❖ Feeling alone ❖ Marital relationship ❖ Social isolation ❖ Role changes ❖ Self-neglect
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The experience of TBI is as much a family issue as it is an individualised issue. Family members experience a range of emotions in dealing with a family member with a traumatic brain injury. This sub-theme will explore the emotional experience family members experience during the journey with TBI.

- **Sub-theme 3.1: Feeling sorry for the person with TBI**

Participant B: *“Ander kere is hy weer so, jy wil hom net toemaak in ‘n wattetjie en jy kry hom jammer want hy het nie gevra om so te wees nie. So ja, jy kry maar daai op en af.”* **Translation:** Other times again, he is like this, you just want to wrap him in cotton wool and you feel so sorry for him because he didn’t ask to be this way. So yes, your emotions fluctuate.

Participant D: *“Jy uhm kom ek sê jou ek dink sy het agtergekom luister almal doen vir my alles, want op daai stadium het jy haar so jammer gekry dat jy nie eintlik wil hê sy moet iets doen nie, jy doen dit maar vir haar, jy weet? Sy kon nog nie met haar geld gewerk het nie, so ek sal haar geld gaan trek en ek sal koop wat sy nodig het en sulke goed.”* **Translation:** You uhm, let me tell you, I think she realised that everyone does everything for me, because at that stage you felt so sorry for her that you didn’t want her to do anything, you’ll do it for her, you know? She wasn’t able to handle her money yet, so I would go and withdraw money for her and I’ll buy what she needs and stuff like that.

Participant H: *“Nee ek dink my dogter voel net soms maar moet sy nie nou leer dat sy dit of dit moet onthou of dit of dit moet dan sê ek vir haar ag ek weet nie, ek voel sy kan nie help nie.”* **Translation:** No, I think my daughter just sometimes feels that shouldn’t she learn that she should remember this or that, or say this or that; then I’ll tell her, oh, I don’t know, I feel she can’t help it.

Discussion of sub-theme 3.1

Living with a person with a TBI creates mixed emotions from feeling sorry for the survivor to feeling frustrated and wanting them to accept some responsibility for their behaviour. It seems as if the quotes above reflect that the participants had mixed emotions about their loved one’s’ injury and consequent behaviour. Family members’ feelings also seem to fluctuate between feeling upset that their family member has to live with a variety of disabilities, to being worn out and frustrated by the demands of caring for him or her (Man, 2002:1033).

- **Sub-theme 3.2: Emotionally draining**

Participant B: “...dit was veeleisend om in die aande huis toe te gaan en te dink, wat gaan jy doen?” **Translation:** ...it was demanding to go home in the evenings and to think, what am I going to do?

Participant D: “Maar ja, dit was baie uitputtend soos ek jou sê, ek was elke môre hospitaal toe en elke aand was ek hospitaal toe. Jy kom eers hier 9-uur by die huis dan moet jy nog jou huisgesin versorg en kos maak...die punt is ek kon nie heeltyd na haar kyk nie. Ek het die werk en ek kon net die maand se verlof gevat het so dit was vir my ‘n probleem. Wat gaan van haar word as ek nou moet werk.” **Translation:** But yes, it was very demanding as I said, I went to the hospital every morning and every evening. You only come home by 9 o’clock and then you have to still care for your family and cook...the point is I couldn’t look after her the whole time. I have to work and I could only take the one month’s leave, so for me it was a problem. What will happen to her if I have to work.

Participant F: “Weet jy ons het, ek het vir nagte, ek weet nie van hom nie, maar ek het vir nagte wat ek nie geslaap het nie en ek het aan die slaap geraak want ek glo nie in slaappille nie, ek drink nie sulke goed nie. En dat ek so moeg was dat dit vir my gevoel het ek sleep deur die volgende dag.” **Translation:** You know, I struggled for nights, I don’t know about him, but I struggled for nights to sleep and I fell asleep because I do not believe in sleeping pills, I don’t drink them. I was so tired that it felt like I was dragging myself through the next day.

Participant G: “Maar die feit dat jy nie weet nie, daai onsekerheid, het vir jou ‘gedrain’, maak jou absoluut moeg. Ja, weet jy, dit is soos maar nog ‘n kind. Jy weet, jy’t nou nog steeds jou ander twee kinders in die huis en nou verg hy ook meer aandag as wat hulle eintlik verg. Jy weet? So, die feit dat dit uitputtend vir jou is, ek meen, jy werk self, jy kom vanaand by die huis, jy’t nog al jou ander normale roetinetjies en pligte wat jy moet doen voor die ongeluk wat reeds taai was met jy kinders en die hele huishouding saam, en nou skielik kom jy met hierdie pasiënt by die huis en hy vat amper nog 25%, weet, van jou tyd. So dit het...dit het veroorsaak dat ek party aande 12 uur / 2 uur gaan slaap het, 5 uur weer opgestaan het om almal weer reg te kry net om weer reg te wees vir die volgende dag.” **Translation:** The fact that you didn’t know, that drained you, it made me so tired. You know it is like another child. You know you still have your other two children and now he demands more attention that they do. So the fact that it is demanding, I mean, you need to work, you come home in the evening, you still have your normal routine and chores that you had before the accident and even then it had been difficult with your children and household. Now suddenly you have this patient at home and he takes about 25% of your time. So it...it led to me getting to bed at 12 o’clock / 2 o’clock and I got up again at 5 o’clock to get everyone ready for the next day.

Discussion of sub-theme 3.2

Dealing with any illness can be exhausting, so much more for family members of people with a traumatic brain injury. The recovery period is long, which in turn can leave family members emotionally drained. Brain injury has a great impact on the family system and places a particularly high demand on the emotional resources of family members. There are countless emotions and impacts on the patient and family

in the process of adjustment (Uomoto & Uomoto, [sa]:5). The participants give different reasons for feeling emotionally drained, such as feeling worried about what to do, going to the hospital to visit every morning and evening, whilst continuing with the usual chores and looking after the rest of the family, being unable to sleep and experiencing the uncertainty of the situation. Whatever the reason might be, it is clear from the quotes given that during the whole process, whether in hospital or at home, they felt emotionally drained. As participant G commented, the uncertainty also contributed to this feeling.

- **Sub-theme 3.3: Pressure to keep going**

Participant B: *“Jy gaan net aan. Daar is nie tyd om te gaan sit en dink.”* **Translation:** You just go on. There isn't time to sit and think.

Participant C: *“Ek gaan aan. Ter wille van my kind gaan ek aan. Dis vir my baie moeilik, veral as hy so buierig is, maar ek moet aangaan.”* **Translation:** I go on. For the sake of my child I go on. It is very difficult, especially if he is so moody, but I have to keep going .

Participant F: *“En dat ek so moeg was dat dit vir my gevoel het ek sleep deur die volgende dag. En dan is ons maar weer op en ons gaan aan.”* **Translation:** I was so tired, that it felt like I was dragging myself through the next day. Then we are up and we are going on.

Participant G: *“Maar, ja, dit is nou goed wat, wat niemand jou mee kan help nie, jy moet nou maar net deur hierdie pad beweeg.”* **Translation:** But yes, it is stuff that, nobody can help you with, you just have to go down this road. .

Discussion of sub-theme 3.3

Most participants felt a pressure to keep going and not stand still, even to pay attention to their own emotional state. Reasons given are that there isn't enough time, their children depended on them, they were so tired but got up every morning and went ahead and there was no-one to help them and they realised they needed to carry on. Kreutzer *et al.* (1994:197) state that the long recovery process, changed personality and altered abilities of the brain of the injured person can be particularly difficult for the family and caregivers. It is also time-consuming and leaves little time to maintain vocational or household responsibilities. The literature didn't specify that family members felt pressure to just keep going, but the researcher understood from the participants that this is how they felt.

- **Sub-theme 3.4: Feeling alone**

Participant B: *“Ja as hy by die huis kom dan begin jy besef, hoor hier, die man is eintlik as mens lelik dink irriterend wat jy nie hierso (hospital) beleef nie. Hierso is dit iemand anders se probleem waar as dit by die huis is, is dit jou probleem. En hy het sy maniere vergeet. Hierso kom jy dit nie agter nie want jy sien hom daai rukkie, ‘n uur of twee, naweke. As hy huis toe kom, dan besef jy wat is die hele package wat jy saam met ‘n breinbesering kry.”* **Translation:** Yes, when he comes home then you realise, but listen, this man is actually, if you’re honest, irritating. Something that you didn’t experience in hospital. Here (in hospital) it is someone else’s problem, at home it is your problem. And he is ill-mannered. Here you don’t realise it because you only see him for a short while, an hour or two and on weekends. When he comes home, then you realise what the whole package is that you receive together with a brain injury.

Participant C: *“My ervaring? Dis net vir my baie erg om hom so te sien. Uhm, dis vir my moeilik om ‘n kind self groot te maak. Dis dis vir my moeilik om alles in die huis alleen te doen, ek is ook moeg in die aande as ek by die huis kom. Ek is nie lus vir sy bakleiery nie. Dis regtig net absoluut die bakleiery wat my onder kry. Ek dink nie daar is iets anders wat ek vir jou kan sê nie. Hy begin my wel nou in die aande met haar help, maar as sy skree, gee hy haar vir my terug. En dis juis dan wat ek besig is om wasgoed te was, skottelgoed te was, klere te stryk of partykeer te stryk, kos te maak. Dan skree sy, dan moet ek haar ook nog vat. Hy sal sommer net loop.”* **Translation:** My experience? It is just terrible to see him this way. Uhm, it is difficult to bring up my child alone, I am also tired in the evenings when I come home. I am not in the mood for fighting. It is just absolutely the fighting that gets to me. I don’t think there is something else that I can say. He is starting to help me with her (baby) in the evenings, but when she cries, he gives her back to me. And it is exactly then that I’m busy with the dishes, sometimes ironing or cooking. Then she is screaming, and I have to take her as well. Hy will just leave.

Participant G: *“Ek dink die grootste skok het gekom uhm, die dag toe hy huis toe kom. Die heelyd was al hierdie mediese personeel daar, wat, wat, wat jou kon ‘support’, wat geweet het hoe om hom te hanteer, wat geleer is in hierdie goed. Nou bring jy hom terug in sy eie ‘environment’, nou jou vriendegroepe, jou familie-groepe, alles, almal sien uit, kan nie wag, wanneer kom Xxx dan nou uiteindelik huis toe nie. Na 4 en ‘n half maande, hier kom ek met hom huis toe, maar ek dink die grootste skok is die dag toe ek in die kar met hom klim en ry en ek besef, nou, OK weet jy wat, nou is dit eintlik jy alleen...Jy weet almal, jy wens iemand kan jou help, jy weet en dis nou net jy en jouself.”* **Translation:** I think the biggest shock came, uhm, the day when he came home. The whole time the medical staff were there, who could support you, who knew how to handle him, who were trained in these things. Now you bring him back into his own environment and your friends, family, everyone is looking forward to when Xxx comes home. After four and a half months, I’m coming home with him, but the biggest shock is the day when you climb into the car and you drive and you realise, you know what, now it’s only you alone...you know everyone, you wish someone could help you, but you know it just you and you alone.

Participant H: *“Dit was vir my nogal ‘n behoefte dat iemand haar, dat haar sussie haar kom help met haar persoonlike goedjies soos bad en hare was, weet sulke goed. Ek moes dit doen, ek, ons moes dit doen. Ons moes haar grimeer. Ek self moes op ‘n stadium leer om haar te grimeer, om hier en daar ‘n strepie te trek vir as ons hier en daar wou uitgaan of ons dogter moes dit doen.”* **Translation:** For me, I felt the need

that someone, like her sister could help with her personal stuff like bathing and washing her hair. I had to do it, I, we had to do it. We had to put on makeup for her. At one stage, I had to learn how to put on makeup for her, to draw a line for her here and there when we wanted to go out or our daughter had to do it.

Discussion of sub-theme 3.4

When patients with TBI are still in rehabilitation, family members often don't realise the full extent of what they are dealing with. They are to a certain extent sheltered by staff who perform most of the caregiving tasks and are comforted in knowing that the staff are responsible. When this person is discharged, participants commented on feeling shocked by the knowledge that this support is gone and that they are now responsible. This leaves them feeling alone and vulnerable. According to the literature, most report good support from the team and from friends, but they tend to feel lost, lonely and in full charge of their relative with a TBI (Masaux & Richer, 1998:440). Families are largely on their own, intensifying their understanding of the permanence and irreversibility of head injury (Williams, 1991:91). There are little formal support structures for people with a TBI and their families in place and family members are left to cope on their own.

- **Sub-theme 3.5: Marital relationship**

Participant B: *"...Hy was altyd daar om mens te ondersteun in jou emosies. Ek meen as jy kwaad raak vir iemand, bel hom en sê vir hom iemand het my omgekrap. Nou kan jy dit nie doen nie, want of hy gaan nie dadelik vir jou kan sê alles gaan olraait wees nie, moenie worry nie of hy gaan opvliënd raak en sê hy sal dit kom uitsorteer. Jy kan nie dit van hom verwag nie, so die emosies ek sou sê mens leer die maar op jou eie self te verwerk...Jy kan nie met hom iets deel en dink hy gaan verstaan nie. Hy sukkel maar om te verstaan as jy met hom praat. Dis asof baie dinge nie grond vat nie, dis soos wind – dit waai net verby."* **Translation:** ...He was always there to support you in your emotions. I mean, if you get angry at someone, then phone him and tell him someone made me angry. Now you can't do that anymore because he is either unable to tell you everything will be OK or he will get angry and say he will sort it out. You can't expect that from him so the emotions, I would say, you learn to deal with on your own...you can't share something with him and think he will understand. He struggles to understand when you talk to him. It is as if a lot of things are not being understood, it is like wind, it blows away.

Participant C: *"Weet jy ons, ons dis asof ons mekaar van voor af moet leer ken. Al ons gewoontes, al ons maniere van dinge doen... Ek het my man vreeslik gemis terwyl hy in die hospitaal was omrede ons baie close mense is, toe het ek hom baie gemis... Ons baklei vreeslik baie so emosioneel maak dit my baie seer. Hy sê dinge wat ek weet hy nie bedoel nie. Uhm, partykeer sê hy dinge en hy die volgende oggend as ek hom aanvat daaroor dan sal hy vir my sê dat hy dit nie kan onthou nie. So partykeer dink ek dat hy seker is hy nie kan onthou nie. Dit het al meer as een keer gebeur. Meer as een keer wat hy nie kan onthou nie... Vroeër jare het hy my laat lag en dan sou ek met hom gepraat het. Nou vee hy sy gat aan my af. Of hy sal vir my sê hoekom lyk*

jy weer so dikbek vanaand? Daar is geen meer belangstelling nie...Ons bly nou in 'n klein plekkie so daar is nie plek om op mekaar te skel en te vloek voor die kind nie. Ons probeer. ons kry dit nie elke dag reg nie. Ons probeer om te praat nadat sy gaan slaap het. Andersins gaan slaap ons maar kwaad. Nog 'n ding wat ons nooit gedoen het nie. Nooit nooit gedoen het nie. ” **Translation:** You know, we, it is as if we have to get to know each other from scratch. All our personal ways and ways of doing things...I missed my husband terribly when he was in hospital because we are very close, then I missed him a lot...We fight a lot and emotionally it hurts me. He says things that I know he doesn't mean. Uhm, sometimes he says things and the following morning if I challenge him about it, he'll tell me he can't remember. So sometimes I think that he can't remember. It has happened more than once. More than once that he is unable to remember...Prior to the accident, he made me laugh and I would share with him. Now he just leaves me. Or he'll tell my why am I so sullen this evening. He doesn't show any interest...We stay in a very small place and there isn't space to shout and swear in front of the child. We try, but don't always succeed. We try to talk after she went to bed. Otherwise we go to bed angry. Something we never did. Never, never did.

Participant G: *“...Ek dink nog steeds die ergste, ergste, as ek vir jou sê vir my, want dit was buite en behalwe sy vir persoonlikheid, uhm, persoonlikheid en goeters -. Ek dink dalk, uhm, die tipe verhouding wat ek en Xxx gehad het voor hierdie ongeluk was hy soos my beste vriend. Hy was my man en hy was my beste vriend. Ek't in die middag huis toe gegaan en ek kon alles wat by die werk my gepla het met hom bespreek. Ons kon oor goed praat, ons kon - in die nagte het ons partykeer in die bed gelê en gelag oor goed wat ek dink niemand anderste sou oor gelag het nie, jy weet, wat vir ons snaaks was, jy weet? Wat 'fun' was en, so ons was ongelooflik gelukkig getroud. Ons het 'n baie, baie goeie verhouding gehad. Die grootste skok is; hier kom my lewensmaat, my man terug, maar hy's nie meer my pël nie. Ek's nog steeds getroud, maar eintlik is ek nou alleen. Hy gaan slaap 6-uur in die aand, dan't ek niemand om mee te gesels nie. Ek kan met niemand meer hierdie goed deel nie, ek kan nie meer met hom lag soos wat ons gelag het nie. Jy weet, ons kan nie met die, ons het nie meer dieselfde goed kan ek met hom oor praat nie. En ek wil so graag met hom praat en goed met hom deel, maar sy konsentrasie of niks is daar nie, jy weet, so dit help nie eers nie. En ek dink dit, dit was vir my, ek het nagte gesit en gedink; Jy weet, ek het einlik nou my pël verloor, my beste vriend is nou ook nie meer daar nie... n Ander ding wat nogals interessant was, skies, wat ek jou dalk al vertel het, uhm, is dat hy soos my gehaat het. Ek kon nie naby aan hom kom nie, glad nie, kon nie aan hom vat nie. Ek moes amper nie eers in dieselfde bed as hy gelê het nie.”* **Translation:** ...I think the worst, worst if I tell you for me, apart from his personality, uhm personality and stuff, I think perhaps was the type of relationship Xxx and I had prior to the accident. He was like my best friend. He was my husband and my best friend. I could go home in the afternoon and discuss everything that bothered me at work with him. We could talk about stuff, we could, during the night we would lie in bed and laugh about stuff I think no-one else would find funny, but it was for us, you know? What was fun and, we were so truly happily married. We had a very, very good relationship. The biggest shock is, I have my life partner, my husband back but he is not my friend anymore. I'm still married, but I'm actually alone. He goes to bed at 6 in the evening, then I have no-one to talk to. I don't have anyone that I can share these things with, I can't laugh with him like we used to. You know, we can't, I can't discuss the same things with him anymore. I really want to, but his concentration is shot, you know, so it doesn't help. I think this, to me it was, I thought for nights, I lost my best friend, my best friend is also

not there anymore...Another thing which was interesting, sorry, maybe I already told you, is that he hated me. I couldn't come near him or touch him. I could almost not even lie in the same bed with him.

Participant H: *"Sy gaan slaap elke aand omtrent sewe uur gaan slaap sy. Winter en somer. Of dit nou nog lig is wil sy gaan slaap. Jy weet sewe uur omtrent gaan slaap sy."* **Translation:** She goes to bed at seven every evening. Winter and summer, whether it is still light outside, you know seven o'clock she goes to bed.

Discussion of sub-theme 3.5

Even though not all participants are married to the person with TBI, the researcher has identified this as a sub-theme because those who are married, have suffered severe losses. Participants commented on how they were used to a certain level of support and with the patient being their husband or wife, that support is now lost. In fact their partner was the source of their need for extra support. They also commented on the severe loss of losing not only their partner but also their best friend. They have in fact experienced a double loss. This also links in with sub-theme four of feeling lost and alone. According to Uomoto & Uomoto, [sa]:5 emotional changes after a TBI may mean that family members may react differently to the person. This may include choosing words carefully so as not to provoke the person with a TBI and over time this can change the atmosphere in a family. Kneipp (1991:168) gave even more insight into the marital relationship: Spouses of people with TBI face unusual, very complicated dilemmas because they have lost their chosen partners who had changed in the meantime (Kneipp, 1991:168). In effect, it seems as if the spouse was now married to a completely different person, one they didn't actually choose.

- **Sub-theme 3.6: Social isolation**

Participant D: *"Ek dink net sy, sy is nie meer sosiaal nie. Jy sukkel baie as jy by voorbeeld sosiaal mense het vir 'n braai of iets. Sy wil nie meer tussen julle sit en gesels nie...En uhm ek het gesien as ons braai, sit ek en sy alleen, dan sal sy nog olraait wees. Sodra jy ander mense begin bykry dan sal sy eerder in die kamer gaan sit."* **Translation:** I just think she isn't sociable anymore. You struggle a lot when you have for example people over for a barbeque. She doesn't want to be among people and talk...And uhm I saw that when we do have a barbeque, and she and I sit on our own, then she'll be OK. When other people come then she goes to her room.

Participant G: *"Jy weet, nou voel die mans half ongemaklik...Partykeer probeer hulle met hom praat en dan, dan is dit vir hulle, weet, jy jy kan nou sien. Dan sê hulle: Joe, maar dit is net nie dieselfde, sal hy ooit weer regkom? En nou is dit na 'n jaar so dat hulle nie eintlik meer by ons kom nie."* **Translation:** You know, the men feel uncomfortable...At times they will try to talk to him and then for them it is, you can see. Then they'll say, *shucks*, it is just not the same, will he ever recover? And now, after a year has passed they don't actually come to visit us anymore.

Participant H: *“Weet jy, ek sou sê, ons vermy nogal sosiale funksies nou. Enigsins waar ons kan, vermy ons sosiale funksies want Xxx voel baie gou uhm eerstens sy is baie moeg nog, sy word gou moeg... Sy kan nie, ten een eerste sy kan nie lank kuier nie. Sy is ook baie rusteloos gewees in die begin – verskriklik. Sy kan nie lekker stil sit nie. So dit is vir haar glad nie lekker om vir twee ure by mense te sit en te kuier nie. Sy sy, dis so erg dat partykeer het mense nog nie eers vir jou koffie of tee aangebied nie dan staan sy al op en sê hoor hier kan ons gaan, weet en dis...Dan vind ek ook dat sy sy kan nie lekker haarself uitdruk, as iemand vir haar ‘n vraag vra, sy sukkel om haarself uit te druk in taal.”* **Translation:** You know, I'd say we try to avoid social functions. Where we can, we try to avoid social gatherings because Xxx very easily feels uhm, first of all she is very tired, she tires easily...She can't, and first of all she can't tolerate long visits. In the beginning she was also very restless, very. She was unable to sit still, so she really didn't enjoy it to sit and visit with people for two hours. She, it is so bad that sometimes people haven't even offered us coffee yet, then she stands up and asks if we can go now...Then I also find that she is unable to express herself, when someone asks her a question then she struggles to express herself in language.

Discussion of sub-theme 3.6

When dealing with a family member that has a TBI, people are in need of social support. According to the quotes above, people with TBI find social gatherings difficult. This complicates matters for family members because in effect it means that they too, are unable to enjoy these gatherings while their family member is finding it so hard. As participant H commented, they try to avoid social gatherings. The literature also states that a huge impact on the family is social isolation. Social isolation may be caused by others' avoidance of the disability, but may also be the person with a TBI's difficulty to maintain and build meaningful relationships (Tate, Lulham and Broe in Webster *et al.*, 1999:596). The quotes also show that in the beginning, friends will try to understand and involve the person with a TBI, but later give up and stop visiting. This is most difficult for the family members as it means that they lose the little support that they have.

- **Sub-theme 3.7: Role changes**

Participant B: *“Soos van die broodwinner gedeelte is verskuif van hom af na my toe. Uhm, hy word basies soos ‘n kind in jou huis, jy versorg hom, jy moet hom rondry, jy moet sorg dat hy betyds is, sorg dat alles gedoen word...Die finansies is nog steeds op jou, so ja dit wat jy voorgee, is nie altyd wat aangaan nie.”* **Translation:** Like the breadwinner part is moved from him to me. Uhm, he is basically like a child in the house, you care for him, you have to drive him around, ensure that he is on time, ensure that everything gets done...The finances is still on you, so yes, what you portray, is not always the reality.

Participant C: *“Vroeër het hy dit vir my gedoen en dit is hel in my huis op hierdie stadium... Weet hy was altyd die broodwinner in die huis gewees, nou, weet my geld was my geld. Hy het nooit eers geweet wat was my salaris nie. Maar nou ongelukkig, weet my salaris moet ook dit en dit betaal, huur betaal, daai prokureur betaal. Weet alles betaal.”* **Translation:** Earlier he would have done it for me and it is hell in my house at this stage... You know he was the breadwinner, my money was my money. He didn't even know what my salary was. Now, unfortunately, my salary must also cover this and that, rent, lawyer. You know, it must cover everything.

Discussion of sub-theme 3.7

Family members have to deal with not only the huge adjustment, but also with certain tasks that were not their responsibility before. For the women, this included financial responsibility that now reverted to them. Marcelissen (in Williams, 1991:92) described stress that can be exemplified by eight situations by families post head injury. One of these stressors is role change. The family may have found ways to cope while the person was in rehabilitation, and may find it difficult to give up these new roles. The person with the TBI may also find it difficult to cope with his or her new role. The first part of giving up roles did not come to light during the interviews, but family members mentioned how difficult the new roles were. According to Kneipp (1991:167) role changes affect each family member and the way they relate to each other. As a result, family functions are affected. This is evident in the two quotes above.

- **Sub-theme 3.8: Self neglect**

Participant C: *“My man en my kind is maar al waaroor ek worry. Ek weet dis verkeerd, my ma sê dit ook elke dag vir my, ek moet bietjie tyd aan myself begin gee, maar ek is nie so 'n tipe mens nie. Ek het nog nooit myself eerste gestel nie. As my man en my kind gelukkig is, is ek gelukkig. As een van die twee sad is, is ek sad. Ja, ek dink ek moet bietjie tyd vir myself begin kry, maar ek is nie geworried nie.”*

Translation: My husband and my child is all that I worry about. I know it is wrong, my mother tells me every day, I must allow myself some time as well, but I'm just not that kind of person. I have never put myself first. If my husband and child are happy, so am I. If one of them is sad, I'm sad. Yes, I do think I must get some time for myself as well, but I'm not worried.

Participant G: *“En toe't ek ook uitgespring en iemand gaan sien en wat ookal en vir my gesê, weet jy wat, ek wil net bietjie myself vind nou, want ek het nou so almal uitgesorteer, né dat ek eintlik op my, dat ek eintlik nie weet waar staan ek nou nie. Weet nie eers stupid goedjies, partykeer kon ek nie onderskei wat is nou reg en verkeerd nie. By die werk kon ek oor simpel goed nie eers 'n besluit gemaak het nie. Ek was so half heeltemal 'confused' kan ek maar sê...En ek meen, toe kom ek agter, ek het eintlik myself in hierdie proses nou verloor. En toe't ek iemand gaan sien en die ou was vir my baie goed, jy weer, hy't my gehelp om weer te sê, OK, hy doen 'n 'life plan', om net, fokus net weer bietjie op jouself, want jy't al hierdie goed en jy't nou jou reserwes uitgedeel. Ek meen, Xxx wat jou man is, wat eintlik hierdie goedjies vir jou*

moet terugsit, of, weet vir jou moet lief wees, en 'n pad saam met jou stap en vir jou kan versorg is, dit is nie meer daar nie.” **Translation:** Then I acted, went to see someone that told me, you know what, I need to find myself, because I was so busy sorting out everyone around me, that I don't know where I'm standing. You know, simple things, at times I couldn't distinguish between right and wrong. At work, I couldn't make a decision about simple things. You can say I was completely confused...I mean, then I realised, I actually lost myself in this process. Then I went to see someone and he was very good. He helped me to say, OK, he did a life plan just to focus on myself, because you have all these things and your reserves are depleted. I mean, Xxx who is my husband, who should help me to put all these things together again, or who is supposed to love me and walk with me and care for me, is not there anymore.

Discussion of sub-theme 3.8

Through the interviews it emerged that family members were so focussed on the person with a TBI that they neglected themselves in the process. Participant G explains how this has affected her and that she was unable to continue like that. According to Man (2002:1033) it was also found that family members were subjected to high levels of stress. They were so involved in the caring process, that they neglected themselves. In this sub-theme, the quotes mirror what the literature says. It also appears that participants found it difficult to make this move towards focussing on themselves and in effect caring for themselves.

3.6.2.4 Theme 4 and sub-themes: Period of rehabilitation

<p>Theme four: Period of rehabilitation</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Rehabilitation experience ❖ Most difficult about rehabilitation ❖ Feelings about discharge ❖ Needs not addressed by team
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The period of rehabilitation follows after the critical IC period. Family members of the participants all attended inpatient rehabilitation. The period of rehabilitation is also very stressful on family members. Stress is not so much linked to a matter of life and death, but the uncertainty about the extent to which the person will recover and to prepare for discharge and their life ahead. It also includes weekend leave of absence, during which the person with a TBI is sent home for a weekend in preparation for discharge.

- **Sub-theme 4.1: Rehabilitation experience**

Participant A: *“Weet jy die rehabilitasie was vir my baie goed gewees. Uhm as ons vat hy het net daar bo gelê. Toe skielik toe sien jy daar is 'n verbetering in hom toe hy*

hier by julle was. Jy kan sien daar is 'n verbetering in hom fisies, hy groet jou, as jy loop dan waai hy vir jou. Jy kan sien daar is definitief 'n verandering in hom gewees. Dit was asof hy weer 'n bietjie, hoe kan ek sê, guts gehad het vir die lewe. Hy was bietjie meer positief gewees.” **Translation:** You know, I found rehabilitation to be very good. Uhm, if we take into account that he only lay in bed upstairs (ICU), you saw progress while he was here. You could see the progress, he greeted you and when you left, he waved. You could see a definite change. It was as if he had more guts for life. He was also more positive.

Participant B: *“OK, jy verstaan dit nie in die begin nie want dit lyk asof hulle vreeslik wreed is om hom skielik hier in die diepkant in te gooi en hy moet skielik alles fisies self begin doen. En uhm wanneer hy huis toe kom, dan besef jy hoekom alles gedoen is, hoekom het hulle nie vir hom 'n bottel gegee nie en gesê drink jou water. Hierso is jou kos, kom, ons voer jou nie. Hoekom moes hy 'n glas vat en drink. So uhm ja, ek sou sê aan die begin is dit moeilik. Ek meen jy kom uit ICU uit waar hy basies opgepiep was, uhm kyk dat hy alles doen. Dit word vir jou gedoen. Jy kry ja, ek, skielik kom jy hier en hy moet alles self doen. Meeste van die dinge moet hy self doen. Ja dis moeilik, dit is maar moeilik. Die eindresultaat is baie keer dankbaar. Dan besef jy hoekom het hulle wat gedoen.”* **Translation:** OK, you don't understand it in the beginning because it looks as if they are cruel to suddenly throw him into the deep end and expect him to do everything for himself. And uhm, when he comes home, you realise why everything was done, why they didn't give him a bottle and said drink your water; here is your food, let's feed you. Why he had to take a glass and drink by himself. So yes, I would say in the beginning it is difficult. I mean you come from ICU where he was wrapped in cotton wool. Uhm checked that he does everything; everything is being done for you. Suddenly you come here and he must do everything for himself. Most of the things he has to do himself. Yes it's difficult, it is difficult. The end result is appreciation. Then you realise why they did what they did.

Participant C: *“Daai mense was wonderlik. Daai mense was so geduldig. Die dae wat ek op my laagste was, wat my man nie wou saamwerk nie, wat hy nie wou eet nie, wat hy niks wou doen nie, daai mense het my daardeur gedra. Daai mense was wonderlik: hulle het vir hom weer geleer lees, loop. Hulle het met hom gesit en vir hom die alfabet geleer. Hulle het, die aande wat ek, ons kon hom nie alleen by water los nie want hy kon nog nie, hy was soos 'n kind dan het hulle hom gebad. Weet ek het probeer om hom te bad, maar ek het my af aande gekry wat dit net vir my te veel was.”*

Translation: Those people were wonderful. They were so patient. The days that I was at my lowest point, my husband didn't want to participate, he didn't want to eat, he didn't want to do anything, those people carried me through it. Those people were wonderful, they taught him how to read and walk. They sat with him and taught him the alphabet. They, the evenings that I, we couldn't leave him alone with water because he couldn't, he was like a child and they bathed him. You know I tried to bath him but I had my off nights that it just became too much for me.

Participant D: *“Hulle was baie goed daar hoor. Regtig baie goed daar. Sy het vir hulle 'n baie moeilike tyd gegee.”* **Translation:** They were very good. Really very good. She gave them a very hard time.

Participant E: *“Ek was baie gelukkig. Die personeel het ons dadelik laat kalm en rustig laat voel, so asof dit 'n huis is. So asof net by ons ander huis is, wat ons net help kyk na jou seun en soos ek jou sê ek het gebid en gevra vir net dat die Here hom moet geduldig maak en rustig maak net dat ons nie altwee met mekaar moet, ek gaan op die ou end na hom moet kyk by die huis, dat ons nie altwee grumpy met mekaar moet bots nie. En humeurige raak en hy wil opspring en loop nie... Dit was vir my wonderlike*

gewees. *Ons het self gesien hoe die personeel met die ander mense werk. Dit was vir my, ek het dadelik tuis gevoel.*” **Translation:** I was very happy. The staff immediately made us feel calm, as if it was a home. As if we were at our other house, they are just helping us by caring for our son and like I said I prayed and asked that the Lord must make him patient and calm that we don’t – eventually I’m going to care for him at home – that we will not both be grumpy and clash with each other...It was wonderful. We saw how the staff treated the other people. For me it was, I immediately felt at home.

Participant F: *“Wonderlik. Weet jy daai aand, hy is die oggend oorgeplaas. Daai aand toe ons instap nê, daai gesig van hom. Weet jy, toe ek instap in daai eenheid en ek kry daai wonderlike reuk, daai blou van die eenheid, dit was vir my so koel so verfrissend. Ek was so dankbaar...Twee, drie dae, ek kon nie glo dis dieselfde mens wat van daar af is na julle toe nie.”* **Translation:** Wonderful. You know that evening, he was transferred the morning, that evening when we walked in, his face. You know, when I walked in and I got that wonderful smell, the blue of the unit, it was cool and refreshing. I was so grateful...Two, three days and I couldn’t believe it was the same person that went there.

Participant G: *“...Ek dink as ek vir hom daar moes uitvat uit waar hy was, uit die Trauma ICU direk huis toe, was dit 10 keer erger...spesifiek die manier hoe julle dit gedoen het. Jy weet daar was ander mense wat nou ook baie seer gekry het, of wat ook al, maar dit is...julle het in groepe gewerk. So onmiddellik dink ek, het Xxx begin agterkom hy moet teruggaan in die, in die sosiale, daar’s mense om hom. En ek meen dit was ook nog, as hy, ek dink dit sou veel erger gewees het vir my as hy nie daar begin het nie, want daar was nou klomp terapeute wat onmiddellik daar met hom kon werk. As ek by die huis moes gekom het en nou gedink het ek kan nou werk, wat nou? Wat nou? Wat maak ek nou met hom?”* **Translation:** ...I think if I had to take him straight home from the trauma ICU the way he was, it would have been ten times worse...Specifically the way you did it. You know there were other people who also got hurt, or whatever, but...you worked in groups. So I think immediately Xxx started to realise he needs to go back into the social, there is people around him. I mean, it would have been so much worse if he didn’t go there because there were a few therapists that started to work with him immediately. If I went home, I would have thought, what now? What now?

Participant H: *“Ja, dit was vir ons goed dat sy hier kon wees en dat sy uhm en ek dink was dit nie vir die rehabilitasie proses nie, sou sy seker nie gewees het wat sy nou is nie. Ek dink nie sy sou so goed gewees het nie, maw sy hulle het haar mooi die tipe oefeninge en goed wat hulle vir haar gee hierdie gym wat hier is jy weet hulle al die oefeninge en die weer leer loop en uhm die ondersteuning wat sy hier gekry het dit het gemaak dat dit net, ek dink die feit dat sy sewe weke hier was het baie baie gehelp vir haar herstel want hulle het dadelik begin...Dit was vir ons ‘n baie groot plus punt die hele proses. Ons was baie goed ontvang hier, altyd jy weet jy was, dit het amper soos jou eie mense gevoel. Hulle het vir ons goeie terugvoering altyd gegee, altyd gesê hoe gaan dit met haar en ek het nie die gevoel gekry en dit was dit het vir my baie beteken dat hulle is lief vir haar, hulle gee om vir haar, hulle kyk mooi vir haar. Hulle is nie kwaai met haar nie weet, hulle hulle het vir my mooi met haar gewerk.”* **Translation:** It was good that she came here and I think if it wasn’t for the rehabilitation process, she wouldn’t have been where she is now. I don’t think she would have been this far, in other words, the exercises they gave her here in the gym, all the exercises and learning to walk and uhm the support that she received made that, I think the fact that she was here for seven weeks helped her recovery because they started immediately...For us the whole process was a big plus. We were received very well, you know it almost felt

like your own people. They always gave us feedback and how she is and I got the feeling; and it meant a lot to me that they loved her, they cared about her, and they treated her well. They didn't become angry, they treated her well.

Discussion of sub-theme 4.1

Rehabilitation is the last step of hospitalisation and most patients go home after rehabilitation. This is the time where family members become very involved in the process and at times it is difficult, as was mentioned by participant B. Regarding this group of participants, all of them seem to agree that rehabilitation was a good experience. Family members also appreciated that the staff treated the person with TBI well and that rehabilitation started immediately. Mazaux and Richer, (1998:436) and Sander *et al.* (2002:649) all seem to agree with the idea that functional independence, reintegration into the community and return to work are objectives for rehabilitation. But improving general well-being and improved quality of life of patients and their families is part of the ultimate goal for rehabilitation. It was evident from the quotes above, that the period of rehabilitation improved patients' and their families' general well-being.

- **Sub-theme 4.2: Most difficult about rehabilitation**

Participant A: *“Weet jy dis uhm, ons het soveel hoop gehad maar elke keer dan sê die dokter ons moenie hoop nie. Hy kan nog steeds doodgaan. En die hele tyd dan dink ons dit gaan nou beter raak, maar dit gaan eintlik slegter.”* **Translation:** You know, uhm, we had so much hope but every time the doctor said we musn't hope. He can still die. And the whole time we thought it would be better now, but in actual fact it was worse.

Participant B: *“Hier besef mens hy moet huis toe kom. Hierso besef jy dat hy moet huis toe kom soos hy is, so dit was vir my die moeilikste.”* **Translation:** Here you realise he has to come home. Here you realise he has to come home just as he is, so that I found the most difficult.

Participant C: *“Ek kon nie 'n verskil sien nie. Ek, die eerste week of wat kon ek nie 'n verskil sien nie, maar die suster het my verseker dat hulle wel 'n verskil sien. Hulle, want in die aande, ek mag nie hom deur die dag sien nie, want deur die dag werk hulle glo intensief met hom. Ons mag hulle eers in die middag sien. Dan kom ek in die middag moeg en geïrriteerd van die werk af, of dan kom ek by hom dan is dit asof ek nie 'n verskil sien nie. Hy is nogsteeds sy verwarde ou self, hy hy wil nie bad nie, hy, hy is, hy is net nie my man nie, verstaan?”* **Translation:** I couldn't see a difference. I, for the first week or so I couldn't see a difference, but the sister assured me that they could. They, because in the evenings, I wasn't allowed to see him during the day, because allegedly they work with him intensively. We were only allowed to see him in the afternoons. When I came in the afternoons, I was tired and irritated from work, and then I couldn't see a difference. He is still confused, he doesn't want to bath, he is just not my husband, understand?

Participant F: *“Ek kan nie, ek kan nie vir jou sê wat was die moeilikste nie. Die feit dat my kind in die hospitaal was nie. Ek is nie gewoon dat een van ons so...gewoonlik*

was dit maar ek gewees, wat gegaan het vir 'n operasietjie. Ek was nie gewoond hy, jy weet, een van my kinders of my man wat in die hospitaal is nie dat ons hom moet besoek en vir so lank nie. Die moeilikste was maar die in en uit ryery.” **Translation:** I can't tell you what was the most difficult. The fact that my child was in hospital. I'm not used to that one of us are so...usually it was me, that went for an operation. I wasn't used to my husband and children being in hospital and that we have to visit for such a long period. The most difficult was the driving in and out.

Participant H: *“Ek dink, ek en my dogter was verskriklik geskok die dag toe ons nou hier kom vir die eerste keer nadat sy vir drie weke uit die intensief gekom het. Toe ons hier kom het haar het ek en sy het ons hier ingestap het altwee van ons se gevoel was, ons het haar nie in haar bed gekry nie en ons gevoel was: hi shame kyk daai vrou was baie klein en dit het gelyk soos 'n meisietjie en ons gevoel was ag siestog ag kyk hierdie meisietjie, kyk hoe lyk sy. Sy lyk asof sy uhm ek wil nou die woord spasties gebruik, haar nek en haar kop het gehang, haar arms gehang, sy het amper so gelê-sit in die rolstoel. En toe sy haar nek so toe sien ons dit is my vrou, so dit was, ons het geskrik.”* **Translation:** I think, my daughter and I were so shocked the one day when we came here after she came out of ICU, after three weeks. When we arrived here, we walked in and both of us felt, we couldn't find her in her bed and our feeling was: shame, look at that woman, she was very small and looked like a girl and our feelings were shame, look at this girl, look how she is looking. She looked uhm I want to use the word spastic, her neck and head and arms were hanging, she was sitting/lying in the wheelchair. When we looked we saw it was my wife and we had a big shock.

Discussion of sub-theme 4.2

According to Mazaux and Richer (1998:437) the period of rehabilitation is extremely stressful for family members. They have a need to be informed with the truth without relinquishing all hope. On the other hand, predicting the prognosis in the early stages remains very difficult. From the quotes, it is clear that family members had hope and that was important for them. Further rehabilitation seemed to be a time of reality check – family members realised that this is the last step of rehabilitation and they might have to take their family member home just like he is, without further progress. For others, this was also a time where they had to accept how badly hurt their family member was. In ICU it is not always possible to notice because they are mostly treated in bed. In rehabilitation, patients are put into a wheelchair and higher demands are placed on them. Some family members did not live nearby and found the driving to and from hospital difficult and exhausting.

•Sub-theme 4.3: Feelings about discharge

Participant C: *“Ja, en die dag toe hulle hom ontslaan het ook, was ek bang om hom huis toe te bring, want ek was bang ek weet nie wat om met hom te doen nie. Hulle het ook vir my gesê ek moet hom nie alleen los nie. Dit dit was vir my die bangste gewees. Wat, wat as ek iets nie reg doen nie? Wat as hy val by die huis en sy kop stamp? Wat*

as hy gly in die bad en sy kop stamp?” **Translation:** Yes, and the day that they discharged him, I was scared to bring him home, I was scared I wouldn't know what to do with him. They also told me not to leave him alone. That scared me the most. What, what if I make a mistake? What if he falls at home and bumps his head? What if he loses his balance in the bath and bumps his head?

Participant E: *“Net dat hy weer sal val en sy sy been sal breek ja. Net dat hy nie sal kan dink wat hy doen nie, want hulle het gesê na 'n breinbesering, ek weet na myne ook, is jy baie meer aggressief, nie aggressief, nie kort van draad, humeurig. En hulle sê jou seksuele vlak is dan hoog ook, hulle het na my breinoperasie vir my dieselfde gesê en ek het dit ondervind met myne, en dit is waarvoor ek bekommerd was, miskien...jy wil hom nou nie oppas soos 'n kleintjie nie, maar jy wil hom nou nie, jy wil hom wys jy gee hom grasie, maar jy kan nou ook nie agter 'n boom aan loop en dophou en so nie. En nou wil hy net die strate invaar en hy wil net gaan kuier.”* **Translation:** Only that he will fall again and break his leg. Only that he won't think what he is doing, they said after a brain injury, I know after mine, you are more aggressive, not aggressive, short tempered. And they say your sexual level is also heightened, they told me the same after my brain operation and I experienced it as well and I was worried about it. Maybe...you don't want to watch him like a child, you want to show him you trust him but you can't walk around after him and watch him. And now he wants to go and he wants to visit everyone.

Participant F: *“Oe weet jy, toe hulle nou vir ons sê hy moet uitgaan, ons was bang. Nee, ek sal vir jou sê ons was bang. Ek was bang ek gaan nou nie vir hom kyk toe moes jy mos nog daai spuit wat ons moet optrek en uhm so aan.”* **Translation:** You know, when they told us he must go out, we were scared. No, I'll tell you we were scared. I was scared I will not be able to look, and then we had the injection as well.

Discussion of sub-theme 4.3

When rehabilitation nears the end, family members are confronted with many emotions, especially fear. Fear for the next part that lies ahead, fear of the responsibility and fear that they might not care for their family member with a TBI well enough and that he or she will get hurt again. According to Kneipp (1991:165) when a patient with a TBI is discharged from hospital, family members and people with TBI often believe that the hardest part is over. Family members often expect that progress will continue at the same rate, especially if progress has exceeded the initial prognosis. Families report that that a person's personality changes are more difficult to handle than the physical changes. The participants in this study didn't really indicate that family members had high expectations upon discharge, but rather that they were scared. In many instances, discharge dates were set by medical aids and therefore it could be that family members felt scared, because discharge hasn't been set by them or by the team. Therefore fears could be linked to premature discharge.

- **Sub-theme 4.4: Needs not addressed by rehabilitation team**

Participant A: *“Nee, ek dink hulle het meer aangespreek as wat ‘n ou eintlik dink. Daar is nie vir ons iets wat jy kan. Dis moeilik so ‘n persoon, dis nie maklik nie. En as ek sien wat julle met hom reggekry het. Vat byvoorbeeld net die klein dingetjies soos tandeborsel. Ons het nooit eers gedink aan dit nie...Ek dink in ‘n mate nè, het uhm help julle mens baie.”* **Translation:** No, I think they addressed more than what you actually think. There wasn't anything that you could, it is so difficult such a person, it is not easy. And when I look what they achieved. For example take something small like brushing teeth, we never even thought about it...I think in a way, uhm, you help a lot.

Participant B: *“Alles wat hulle van hulle kant af doen sou ek sê is aangespreek. Kyk, ek was voorbereid dat hy kom huis toe en dit gaan nie maklik wees nie en al daai klas van dinge is met my bespreek. So daar is nie regtig iets gewees nie.”* **Translation:** Everything from their side was addressed. Look I was prepared when I brought him home that it will not be easy and all those kinds of things were discussed with me.

Participant D: *“Nee, ons was 100% voorbereid op dit ja. Nee, dit het hulle vir ons baie mooi verduidelik hoor. Sy gaan hierdie stadions kry en op hierdie stadium gaan dit so gebeur en sy gaan woede-uitbarstings kry omdat sy nie meer dieselfde mens was nie. Sy gaan agterkom sy is nie meer dieselfde mens nie. Sy kan nie meer so sosiaal verkeer soos voorheen nie.”* **Translation:** No we were prepared 100%. No they explained it nicely. She will go through this stage and at this stage this will happen and she will have anger outbursts because she isn't the same person anymore. She will realise she is not the same person. She will not be able to function socially like she did before.

Participant E: *“Nee, hulle het absoluut met ons oop kaarte gespeel van die begin af. En na hulle hom so paar dae, na hy so paar dae daar was, ek dink so week was hy daar, so plus minus die tweede, derde dag toe roep hulle ons in, maak hulle ‘n afspraak met ons, ek en my man, hulle wil met ons praat oor sy vordering. Al die susters, die personeel wat met hom besig was en die dokter, weet die arbeid en die spraak, die fisio, die een doen dit. Elke personeellid was daar gewees. Dan het hulle hulle verslag oor hom gegee, hoe vind hulle hom, hoe vorder hy, wat wat wat. Die dokter het toe gevra wat is ons bekommernis, ons grootste bekommernis as hy nou huis toe gaan. Waarvoor is ons bang om te doen.”* **Translation:** No, they were very honest with us from the beginning. After he had been there for a few days, I think a week, more or less the second or third day, they called us in, made an appointment with me and my husband to discuss his progress. All the sisters, staff that worked with him and the doctor, you know the occupational, speech and physio, this one does that. Every staff member was there. They gave us a report on him, what they found, how he is progressing. The doctor asked what our biggest concern was, our biggest concern if he had to go home right away.

Participant H: *“Nee wat, ek was regtig tevrede. Nee wat ons was baie tevrede.”* **Translation:** No, I was very satisfied. No we were very satisfied.

Discussion of sub-theme 4.4

The literature states that family members have a need to be informed about the truth without relinquishing all hope. The prediction of the prognosis in the early stage remains very difficult (Mazaux and Richer 1998:437). All participants agreed that they

were adequately informed and prepared for discharge. They all also looked back on the rehabilitation with satisfaction and confirmed that their needs were met.

3.6.2.5 Theme 5 and sub-themes: Period post discharge

Theme five: Period post discharge	Sub-themes: <ul style="list-style-type: none"> ❖ Very stressful, demanding, busy time ❖ Constant responsibility ❖ Feeling guilty ❖ Patience ❖ TBI person determines emotional state ❖ Financial implications
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When a person with a TBI is discharged from rehabilitation, a period of adjustment follows, not only for that person, but for the family as well. The support from the rehabilitation team is not there anymore, and family members need to adjust to their new role as caregivers. It is often a time where family members need to set up new routines and get to know each other. The stress of hospitalisation might be over, but family members are confronted with a variety of other issues to deal with.

- **Sub-theme 5.1: Very stressful, demanding, busy time**

Participant A: *“Weet jy in die dag moet jy werk en in die nag moet jy na hom kyk. So jy kan een of twee aande dit doen, wat van die derde en vierde aand? So jy sal nie, uh as jou familie jou nie help nie gaan jy dit nie alleen regkry nie...ons het Xxx daar gehad en al wil die gesin help, eintlik trap ons op mekaar se voete. Uh, daar is maklik struwelinge so in ‘n huis... Jy weet ek het die wekker gestel dan maak ek iemand wakker, dan hoor ek daardie een gaan nie dan staan ek maar self op. Jy kan nie sy medikasie oorslaan nie, jy moet dit gee. Uh so dit is verskriklik.”* **Translation:** You know, during the day you have to work and during the night you have to look after him. So for one or two nights you can manage, but what about the third or fourth night? So you won’t be able, uh if your family doesn’t help you, you won’t be able to manage...We had Xxx there and even though the family want to help, it is actually crowded. There can easily be confrontation...You know, I had to set my alarm clock then I wake someone else, then I hear that one doesn’t go, then I go myself. You can’t skip his medication, you have to give it. Uh, it is terrible.

Participant B: *“Daar is nie tyd vir afbreek en huil en sulke klas van dinge nie, daar is nie. Jy voel maar partykeer dinge raak te veel en dan raak jy maar kort van draad en humeurig en ag jy wil alleen wees. Baie keer is dit nie moontlik nie....Veeleisend somtyds. Ek het begin want hy wou weet wat’s dit, wat’s dit? Hoekom so, hoekom dit, hoekom bel die een jou en dan, ek het begin om net vir hom te sê Xxx, want dit is hoe dit is...Dit is regtig partykeer veeleisend.”* **Translation:** There isn’t time for breaking down and crying and those kinds of things, there isn’t. Sometimes you feel, things become too much, then you are short-tempered and you want to be alone. Many times,

it isn't possible...Demanding at times. I started, because he wants to know what is this, what is this? Why this, why that, why is this person phoning you, and I started to say to him, Xxx because this is how it is...Sometimes it is really demanding.

Participant C: *“Ek was doodmoeg in die aande, ek moes sorg dat ek voor hom op is in die oggende. As hy in die nag net gedraai het was ek wawyd wakker. Ek het gaan slaap lank nadat hy gaan slaap het om seker te maak hy slaap, hy val nie van die bed af nie.”* **Translation:** I was so tired in the evening and I had to ensure that I'm awake before him in the mornings. If he turned around during the night, I would be wide awake. I went to bed long after him to ensure that he was sleeping, and he doesn't fall off the bed.

Participant D: *“Ja dit was moeilik, toe ons by die huis kom ook, jy weet sy kan nie loop nie en jy moet haar half vashou om in die bad te klim, jy moet haar weer keer dat sy nie val nie. Sy het nog steke in die kop, so jy is maar altyd bang dit bloei weer dan moet sy terug.”* **Translation:** Yes, it was difficult, when we arrived at home, you know she couldn't walk and I had to hold her climbing into the bath and you have to keep her from falling. She still had stiches in her head so you are always scared that it will bleed again and she has to return to hospital.

Participant G: *“...As ek nou moet terugdink, dan dink ek, ek, ek kan nie vir jou sê hoe't ek dit gemaak nie. Ek weet nie. Met min slaap, en baie stres, of wat ookal, maar jy, as, daai tyd gaan jy eintlik nou maar net aan, ek dink dit is natuur wat eintlik, wat inskop. Toe ons nou by die huis aankom en so aan, toe't ek nou agtergekom, toe't, jy weet, hy't nou bietjie meer, weet, 'support' – kan ek nou maar sê – nodig gehad in die sin van; nou moet hy binne-in die bad klim, hy was te swak, ek moet hom uithelp. So ek moes onmiddellik, uhm, besef het die eerste twee maande moes ek daar wees as hy gaan bad, as hy aantrek...”* **Translation:** ...When I think back, I can't tell you how I made it. I don't know. With very little sleep, a lot of stress or whatever but if you're in it, you just go on, I think it is part of nature that kicks in. When we arrived at home, I realised you know, he needs more support, in the sense of climbing into the bath. He was too weak and I had to help him. So I had to realise immediately, I have to be there when he baths, when he dresses...

Participant H: *“Ek dink die eerste paar kere toe sy daar gekom het was sy nog heeltemal gedisorïenteerd. Ek, sy was vir my nog heeltemal baie baie rusteloos. Ek moes haar, dan sê sy vir my sal jy my in die bed sit dan sit ek haar in die bed. En nes ek haar toemaak in die bed, dan dan dadelik is sy weer op dan sê sy ek wil net gou toilet toe gaan. Dan sê ek vir haar jy was nou net by die toilet, maar ek wil weer gaan. Dat sy onwillekeurig haar klere begin uittrek, dan trek sy weer aan, dan trek sy goed oor mekaar aan. Dit was 'n erge erge rusteloosheid in haar wat ek nog nie mooi weet hoekom dit so is nie, daar het 'n...sy was baie erg...later het 'n, toe sy nou al 'n bietjie beter is as ons kuier of as ons by iemand sou eet of as iemand by ons sou eet het sy al om die tafel geloop. Sy kon nie stil sit en eet nie. Sy sou 'n happie vat en dan loop sy. Sy sal daai hele ete sal dit so deurgaen en so was dit in die nag ook. Ek moes werk, ek moes aangaan met my werk en ek dit amper soos babysit in die nag. Jy moes die hele nag was ek op, ek was doodmoeg, want sy bly opstaan. Sy bly opstaan. En sy kon nie alleen loop nie, dan's ons bang sy's swak, sy moes met ondersteuning loop.”*

Translation: I think the first few times when she came home she was still completely disorientated. She was also very restless. I had to, she asked me to put her to bed, and then I did. Just as I tucked her into bed, she would get up and say she wants to go to the toilet. Then I'd tell her, you just went to the toilet, but she wants to go again. She undressed herself involuntarily, and dressed herself again, and put on clothes over each other. It was a terrible restlessness and I still don't know why, there was a...it was

terrible...later when she was a bit better and we visited people or went for a meal at people's home she would walk around the table. She couldn't sit still and eat. She would take one bite and then she walks. It would carry on the whole meal and all through the night. I had to work, I had to carry on with my work and it was almost like babysitting during the night. I was up the whole night; I was so tired because she kept getting up. She kept getting up. And she couldn't walk alone, we were scared because she was so weak and had to walk with support.

Discussion of sub-theme 5.1

After discharge from hospital, family members have to go through an adjustment period during which they try to get used to new routines and often a new person. This together with normal tasks may lead to an extremely busy time. Participants commented on how busy it was with very little sleep. One participant commented on how it felt like babysitting during the night. There were also cognitive effects of the TBI that complicated matters and family members were for the first time solely responsible without the support of the hospital. Kreutzer *et al.* (1994:197) state that the long recovery process, changed personality and altered abilities of the brain-injured person can be particularly difficult for the family and caregivers. It is also time-consuming and leaves little time to maintain vocational or household responsibilities. According to Uomoto & Uomoto, ([sa]:1) family of the brain-injured person have to cope, manage and endure stresses and burdens during the recovery. For the participants, the relief of having the person at home after a long hospitalisation, is contrasted with many stressors and being extremely busy not only with caregiving tasks, but also with normal daily tasks and at the same time adjusting to the new routines. This all being done while extremely tired due to lack of sleep.

- **Sub-theme 5.2: Constant responsibility**

Participant A: *“Jy slaap nie eers in die nag nie, jy is wakker. Jy sien die horlosie elke uur omgaan.”* **Translation:** You don't even sleep during the night, you're awake. You see the clock turn over every hour.

Participant B: *“Ja ag weet jy, baie keer cope ek nie. Dit voel of ek rond hardloop sonder einde. Die babatjie is mens nog in die aand ook aan die gang. So, nee ek cope nie regtig nie, as mens dit so kan noem. Ja, party dae beter as ander.”* **Translation:** Yes oh you know, many times I don't cope. It feels as if I'm running around on end. The baby also keeps me busy during the night. So no I don't really cope if you can put it like that. Yes, some days better than others.

Participant C: *“Ek kon hom nie alleen los nie, ek was te bang...seker gemaak hy gaan bad. Ek het lank by hom gesit in die aande weet in die badkamer om seker te maak dat hy bad, mettertyd hom geleer om te bad.”* **Translation:** I couldn't leave him alone, I

was too scared...had to make sure he bathed. I sat with him in the evenings in the bathroom to make sure that he bathed, and eventually taught him to bath.

Participant D: *“Uhm, OK in die begin kon sy haarself glad nie help nie en goed. Sy het vreeslik baie afhanklik geraak van my. Sy het nou Julie-maand het sy uitgekome verlede jaar toe het ek Augustus maand verlof gevat om na haar om te sien...”*

Translation: Uhm, OK in the beginning she couldn't help herself. She became very dependent on me. She came out in July and August I took leave to take care of her...

Participant E: *“...hy sal na sy vriende toe wil gaan, dan is ek bekommerd want ek is bang hy, hulle kyk nie na hom nie. Ek sê nie hulle moet hom baby nie, maar hy mag nie meer gerook het nie want na die long seergekry het...Die kans vir epilepsie is waarvoor ek bekommerd was. Hy gaan dit weer doen. Ek het vir al sy vriende om hom gewaarsku, gesê hy mag nie. Ek weet hulle kan nie, hulle probeer om nie om hom te rook nie; hulle moenie hulle hele lewe stop as gevolg van hom nie, maar hy moet nog so normaal as moontlik funksioneer sodat hy kan tuis voel. Maar as hy wil rook moet hulle vir hom sê nee jy mag nie rook nie, die dokter het gesê jy mag nie, daai dinge. Ek het hulle mooi gevra en hulle almal het saamgewerk, maar hy het toe weer self begin rook.”*

Translation: ...He will want to go to his friends, and I am worried because I am scared he, they don't look after him. I'm not saying they should baby him, but he wasn't allowed to smoke after his lung got injured...I was worried about the possibility of epilepsy. He will do it again. I asked all of his friends to warn him that he is not allowed. I know they can't, they try not to smoke in front of him, they shouldn't stop their lives because of him, but he should function as normal as possible in order to feel at home. But if he wants to smoke, they should tell him: no, he is not allowed; the doctor said so, that type of thing. I asked them nicely to work with me and they did but he started to smoke on his own.

Participant G: *“Ek is die verantwoordelike een met die 2 kinders. So mens weet nie tot waartoe is hulle in staat nie, en ek gaan nie daar sit en dit 'judge' nie, so ek ontwyk eerder die situasie en dan later as ek sien dis nou kalmer of wat ookal, 'even' vir die kinders se onthalwe, jy weet, dit is, dit is stremming vir daai kinders, want hulle kan, ook kan hulle nie verstaan nie.”*

Translation: I am the responsible one with two children. You don't know what he'll do and I'm not going to sit there and judge, I'll rather avoid the situation and then later when I see it's calmer or whatever, even for the children's sake, you know, it is stressful for them because they can, they can't understand.

Participant H: *“Ja wel, ek dink dis maar nog steeds die feit dat sy nie mag bestuur nie so al die gesinsverantwoordelikhede kom op my neer, maw ek moet haar by haar ballet of skoolfunksies besorg jy weet? Of ek moet selfs nou nog omsien dat daar kos is of ek moet dit reël. Al reël ek dit nou met haar en sê hoor hier sal jy vir ons dit en dit maak, herinner haar om die kos te maak. So dis maar die hele ding van jy werk. Ek het nog die besigheid van die boerdery ook. En ek moet nog amper al haar take ook nog amper oorneem... Sê nou maar ek sê ry tot by die teerpad, ons bly op 'n plaas, kry vir xxx (daughter), na skool. Dan daai tyd, al het ek nou 'n rugby- of tenniswedstryd aan die gang by die skool, dan moet ek nou onthou o ja ek moet nou half-drie weer bel en hoor het sy onthou om te ry. Het sy nie aan die slaap geraak nie, het nie sommer op die bed gaan lê nie, want dit ook al gebeur...So dit is ek moet die heelyd amper check, hoor hier doen sy, onthou sy wat sy moet doen.”*

Translation: Yes well, I think it is still the fact that she can't drive a car so all the family responsibility is mine, in other words I have to take her to ballet or school functions, you know? Or I have to make sure there is food, or organise it. Even if I just organise it with her, listen will you make us this or that and I have to remind her to make it. So it is the whole thing that you're working. I still have the business of the farm as well. I have to take over all of her responsibilities

as well...say she drives to the tarred road (we live on a farm); fetch Xxx (daughter) after school. That time, whether I have a rugby or tennis match at the school, I must remember I must phone at half past two to check if she remembered to go. Has she not fallen asleep as that has happened before. So I must check the whole time, listen did she do, does she remember what she has to do.

Discussion of sub-theme 5.2

None of the participants had any assistance or respite from the role of caregiving. They and they alone were responsible for this person with a TBI. This sub-theme links well with the previous one. Not only is this time after discharge very busy and demanding, but participants found the constant responsibility difficult. Some of the patients with TBI had progressed to such an extent that they didn't need full time care, but it was as if they couldn't be trusted with the responsibility. Family members still had to ensure that everything got done. That meant that all of the responsibility of the household or children fell on the participants. One participant commented on how she felt responsible even if the person wasn't with her. She felt that no-one could be trusted with the important task of keeping this person safe. Family members were also responsible for hygiene tasks – ensuring that the person with a TBI bathes and takes care of himself or herself. Marcelissen (in Williams, 1991:92) described stress of families post head injury and one of the stressors is prolonged caretaking. Many people do not have a relief or even a temporary respite from the demands of taking care of a brain-injured family member. This leads to family members always bearing the responsibility.

- **Sub-theme 5.3: Feeling guilty**

Participant B: *“Ek is kort van draad. Moenie my ‘n ding twee keer vra nie, ek is geïrriteerd. Baie keer loop Xxx deur want ek bedoel hy is nie daai tipe mens wat vir my sal sê weet jy ek het jou niks gedoen nie, los my net uit nie. Ek sal met hom geïrriteerd raak en sê kom net by, regtig kom nou net. So uhm, (silence)... So ja, mens voel skuldig, ander kere is dit net dis iets wat jy moes gesê het. Wanneer jy skuldig voel, is dit oor jy dit op die kinders begin, uhm kinders is maar kinders.”* **Translation:** I have a short temper. Don't ask me something twice or I become irritated. Many times Xxx suffers because he's not that type of person that will tell me leave me alone, I didn't do anything to you. I will be irritated with him and tell him to pull himself together. So uhm (silence)... So yes, you do feel guilty, other times it is things that had to be said. When you feel guilty, it is because you start to take it out on the children, children are children.

Participant C: *“Oor die dinge wat ek vir hom sê wat onnodig is, as ek kwaad is. Partykeer ook is ek baie spyt dat ek nie vir hom gesê het bly by my nie, dat ek vir hom gesê het gaan kyk jy rugby. Want as hy nooit daai aand gaan rugby kyk het nie, was hy nooit in die ongeluk nie.”* **Translation:** About all the things that I say to him when I'm angry that is unnecessary. At times I regret not telling him stay with me, that I told him

go watch rugby. If he didn't go watch rugby that night, he would never have been in the accident.

Participant D: *“Aan die ander kant voel jy ook skuldig, sy kom nou nie rerig uit nie. Wanneer gaan sy nou bietjie uitkom as jy haar nie saamvat nie? So jy voel skuldig daaroor, maar dan dink jy nou weer aan die ander kant eerder dat ek nou die naweek geniet as sy daar is as wat jy haar saamvat en sy krap almal om.”* **Translation:** On the other hand you feel guilty, she doesn't come out much. When will she come out if you don't take her along? So you do feel guilty, but then on the other hand, you want to enjoy your weekend and if she goes along she might upset everyone.

Discussion of sub-theme 5.3

Participants indicated that they felt guilty about many things but mostly about saying something to the person with TBI when they are angry or irritated. One participant indicated that she felt guilty about the accident, that she didn't ask her husband to stay at home. Another participant indicated that she feels guilty for not taking the person along to social gatherings because she doesn't come out much. Williams (1991:89) state that after the initial crisis, there is not clear-cut indication as to when the crisis is over, as it becomes redefined by the anxiety about the uncertainty about the future, guilt and the belief by society that when a person becomes sick, he or she is cured and sent home. Johnson & Higgings, Roger and Kreutzer, Zegeer (in Painter, 1990:70) state that family reactions to TBI include “severe anxiety, denial, anger, withdrawal from other family members, poor decision making skills, rigidity, low frustration tolerance and guilt”. According to the literature it appears that feelings of guilt is common when dealing with a family member who had a head injury.

- **Sub-theme 5.4: Patience**

Participant C: *“Dit dit het baie geduld van my gevat en ek is nie 'n geduldige mens nie. Hy het my eintlik geduld geleer.”* **Translation:** It took a lot of patience from me and I am not a patient person. He actually taught me to be patient.

Participant D: *“Jissie, ek het baie geduld hoor, ek het eintlik te veel, maar soos ek sê party dae krap dit jou regtig om...”* **Translation:** Goodness, I have a lot of patience, actually too much but like I say, some days it just upsets you ...

Participant E: *“Daar was nie tyd om ongeduldig te raak nie. Daar was elke keer iets anders gewees. Byvoorbeeld dis asof jy heelyd sit en fokus op hom op sy vordering, sodra jy vordering sien dan asof daai titseltjie vordering jou geduld toesmeer, jou jou “grumpiegeid” rustig maak. Net 'n titseltjie vordering het ek klaar vir mense gesê daar is 'n ligpunt, daar daar's hoop. En dit het my geduldig gehou.”* **Translation:** There wasn't time to become impatient. Every time there was something else. It is as if you sit and focus on him and his progress and when you see progress it covers up your patience, it makes you calm. Just a little bit of progress and I told people, there is light, there is hope. And that kept me patient.

Participant G: “Ja, hy’t eintlik vir my vere gevoel. En op ‘n dag toe sit ek met hom, toe sê ek vir hom, hy moet nou beseft; jy kan my onthou. Kan jy my onthou? Ja-nee, hy kan my onthou – hoe kan hy my nou nie onthou nie? sê hy. Toe sê ek; Maar nou moet jy onthou, ek was jou vrou, ek was nie jou vriendin nie, ek was niemand anders nie, maar nou sê ek nou vandag vir jou, of jy nou daarvan hou of nie hou nie, dan gaan ek van nou af vir jou leer om van voor af van my te hou. Maar van my gaan jy van my hou. Ek settle vir niks minder as dit nie...In die oggend as hy opgestaan het, sê ek; Jy’t nie vir my môre gesê nie. Môre. Sê ek; Dis nie hoe jy my môre sê nie, ek is jou vrou, ek is nie jou kind of jou pêl of jou vriend of jou vriendin nie, jy moet my soen. Dan sal hy so gekom het en jou so, gestamp-soen het. Dan sê ek; Baie dankie, môre, lekker geslaap? en aangegaan. As hy wou ry, as hy uity by die huis of wat ookal, sal ek vir hom sê; Jy mag nie ry, jy’t my nie gegroet nie. OK, baai. Sê ek; Maar dis nie goed genoeg nie, want ek is jou vrou, jy groet nie my nie so nie. Ek het dit so vir ‘n week gedoen, en nou, nè, is hy so gesteld op dit... dis klein goedjies, wat ek net besluit het, ek gaan net nie ‘settle’ nie, al moet ek hom nou van voor af goed leer, dan leer ek dit vir hom...En dan, ander ding is maar net, as daar iets is wat ek nou geleer het uit die hele besering uit, is dit nou geduld. Kyk, met sulke goed moet jy baie geduld en nog geduld en baie geduld hê (laughs).” **Translation:** Yes, he felt nothing for me. One day I sat and said to him he must realise he can remember me. Can you remember me? Yes he can, how can he not? Then I said, but then you must remember I am your wife, not your friend, not someone else but I’m telling you today, whether you like it or not, I will teach you to like me again. But you will like me. I will not settle for anything less. In the mornings when he woke up I told him you didn’t greet me. Morning. It told him, that is not how you greet me, I’m your wife not your child or your friend, you must kiss me. Then he would give me a bump kiss. Then I would say thank you very much. Morning, did you sleep well? If he wanted to go somewhere, I’ll tell him you’re not allowed to go, you didn’t greet me. OK, goodbye. I would tell him that is not good enough because I am your wife and you don’t greet me that way. I did that for a week, and now he is so focussed on it...it’s the small things and I decided I will not settle for less, even if I have to teach them to him from the beginning then I will...One other thing that I’ve learned is patience. Listen, with these types of things you have to have a lot, a lot of patience.

Participant H: “Ek dink partykeer kom die ongeduld maar ‘n bietjie (Children). Weet ek self, het my ook al betrap hoor hier ek is maar bietjie ongeduldig met haar maar uhm ek dink dit is maar menslik. Jy kom maar net op ‘n punt.” **Translation:** I think at times they (children) are impatient. I know I realised that at times I am impatient with her but I think it is just human. You just reach a point.

Discussion of sub-theme 5.4

Having to tolerate change and hardship takes its toll. Participants commented on how they thought of themselves as being patient, but that their situation and family member with TBI led them to either learn more patience or at times lose their patience. One participant said that you reach a point where you’re unable to be patient. The behaviour of participant G, having the patience to not leave when her husband did not treat her the way he used to, but to teach him to like her again, is extraordinary. Again the issue of lack of time and impatience, whether it is with the person with TBI or with

his or her progress, also came up. When studying the literature, the researcher only found the quote below when looking at patience. It does not fully describe the issue of patience like participants shared, but refers to anger and aggression. “Over a prolonged period of time of walking on eggshells, family members may become weary and lose their patience with the survivor, which may in turn make the survivor more prone to anger outbursts” (Uomoto & Uomoto, [sa]:5). In this sub-theme participants did not specifically refer to patience with anger outbursts and aggression.

- **Sub-theme 5.5: TBI person determines emotional state**

Participant B: “Ja en dit hang maar ook af van hom af. Jy kan regtig, as hy die oggend opgestaan het en hy gaan niks doen nie, dan is dit so en dis veeleisend. Dan moet jy agter hom loop en fisies vir hom sê en alles met hom doen. So ja, jy het maar jou af en jou op en jou emosies loop maar saam met daai af en op van hom.”

Translation: Yes it depends on him. You can really see, when he gets up in the morning and he won't do anything, then that is the way it is and it's demanding. Then you have to walk around after him and physically tell him and do everything with him. So yes, you have ups and downs and your emotions depend on his ups and downs.

Participant C: “En soos ek nou-nou vir jou gesê het, ek sit my man en my kind se geluk eerste, voor ek myne sit. As hy ongelukkig en frustreerd is, is ek ongelukkig en frustreerd”. **Translation:** Like I told you before, I place my husband and my child's happiness first, before my own. If he is unhappy and frustrated, I am unhappy and frustrated.

Participant D: “Dis baie moeilik hoor en wat ook gebeur veral as jy nou in 'n verhouding is en jy het haar naweke en sy krap jou om dan haal jy dit op hom uit. Dit gebeur redelik baie. As sy die kind omkrap dan haal dit kind dit op my uit en op die ou end van die dag is ek en die kind die moer in vir mekaar. Of die kind sal vir my sê Ma vat haar part. Of sy sal vir my sê vat jy maar jou kind se part. Partykeer gaan dit so en op die ou end van die dag is daar so 'n atmosfeer in die huis, niemand wil met niemand praat nie.” **Translation:** It is very difficult and what also happens is when you're in a relationship and she is with you over weekends and she upsets you, then you take it out on him. That happens a lot. If she upsets the child, then she takes it out on me and at the end of the day we are all angry with each other. Or my child will tell me I take Xxx's side. Or she'll tell me I take my child's side. At times that is the way it is and at the end of the day there is an atmosphere in the house and we are not speaking to each other.

Participant H: “Jy weet dit hang af in watter gemoedstoestand sy is. As my dogter sê mamma kan ek sê nou maar vanaand by die of die gaan kuier of vanmiddag by die een gaan kuier dan dit hang van haar gemoedstoestand af. Sy sal net summier sê nee sonder rede sonder enige rede sal sy net sê nee jy kan nie want sy voel nie lekker nie.” **Translation:** You know, it depends in which mood she is. If my daughter asks her if she can visit this or that person then the answer depends on her mood. She will say no, without any reason she will say no because she is not feeling well.

Discussion of sub-theme 5.5

The participants of this study have got into a mode where they have so focussed on their family member with a TBI and their emotions that they are not paying attention to their own emotional state. They in fact feel unhappy and frustrated when the person with TBI feels unhappy and frustrated. Further, the family member with TBI has had such a big impact on family functioning and the quality of family life, that other family members have to absorb the frustrations which in turn cause a negative atmosphere in the house. The quotes above also show that the person with TBI reacts on how he or she feels and is unable to guard responses, his or her reaction has a big impact on other members in the family. According to Uomoto and Uomoto, ([sa]:4) a dysfunctional reaction to the situation with a family member with TBI is to overcompensate for the decreased functioning of the person and make him or her the centre of family life, inviting other members into a lifestyle which does not accommodate their own needs and goals. According to the quotes given by participants, it seems that this is exactly what had happened.

- **Sub-theme 5.6: Financial implications**

Participant A: *“Alles het omtrent hier by R4 000 gewees en dis verskriklik baie vir ‘n familie om by te dra alhoewel my broers, ons het maar almal rande bygesit. Jy kan nie soveel bymekaar sit nie, dis onmoontlik vir ‘n familie om soveel bymekaar te kry. Weet jy jy verstaan nie die probleem wat met so ‘n ding gepaard gaan nie totdat dit jou tref nie. Jy weet uh, skielik moes ek geld iewers kry...Ek het ‘n besigheid en ek het hom leeg getrek.”* **Translation:** Everything was around R4 000 and that is a lot for a family to contribute even though my brothers all helped. You can’t put that much together, it is impossible. You know, you don’t understand the problems associated with such an issue until it happens to you. You know, uh, suddenly I had to find money somewhere...I have my own business and I emptied the account.

Participant B: *“(Crying). Dis ‘n aanpassing om van ‘n hele salaris, ‘n hele finansiële...hoe kan mens dit stel? Van jou inkomste skielik na ‘n kwart toe te gaan... Kom ons sê maar die finansies. Dis vir my die grootste hoofpyn.”* **Translation:** (Crying). It is an adjustment to go from a whole salary, ‘n whole financial...how can I put it? Your income went to a quarter of what it was...Let’s say the finances. It worries me the most.

Participant C: *“Ons het verlede jaar April maand in ons eie plekkie ingetrek, alles alles weer verloor. Alles weg. Ons sit nou met soveel mediese skuld, want ons het nie ‘n baie hoë medies nie, ons het ‘n baie lae medies, maar dit wat die medies gedek het, is ek baie dankbaar daarvoor. Ons het so R40 000 se mediese skuld...My ouers en sy ouers sorg op hierdie stadium vir my kind, sorg dat sy melk het, dat sy doeke het. Hy kan nie meer, uh hy is gedemote as jy dit so kan noem by die werk, want hy kan nie meer dit doen wat hy kon gedoen het nie...Dis tog nie lekker om vandag in die winkel te stap. My kind wil ‘n chocolate hê. As ek hierdie R2 nou vat vir die chocolate het ek nie*

brood vanaand nie. Dit is regtig hoe dit nou met ons gaan.” **Translation:** Last year April we moved into our own place, we lost everything again. Everything is lost. We have a lot of medical debt because we don't have a very high medical aid, we have a low medical aid but that what they did pay for, I am grateful for. We have medical debts of about R40 000 ...My parents and his parents care for my child, ensures that she has milk and nappies. He was demoted at his work because he was unable to do what he did before...It is not nice, walking into a shop. My child wants a chocolate. If I take this R2 for the chocolate, we don't have bread tonight. That is how it is with us.

Participant D: *“En ek het juis die bediende vir haar gekry om haar nou op te pas omdat ek nie deur die dag by die huis is nie om te kyk dat sy kos het en sulke goed. Toe dit nou op die ou end van die dag by betaal kom, toe wil sy nie 'n sent gee daarvoor nie en ek meen dit was nie vir my nie.”* **Translation:** I hired a domestic worker to watch her during the day because I am not at home, to ensure that she has food and that type of thing. When it came to paying at the end of the day, she did not want to contribute one cent and I mean it wasn't for me.

Participant F: *“Ag, dis vir ons moeilik uhm, gelukkig dat jy darem nou nog bietjie geld gehad het en 'n pakket wat nou nie veel is nie, wat hy gekry het. Hy het nou gaan teken vir sy eerste UIF. Daar sal seker 'n paar rand kom tot tyd en wyl hy dalk nou êrens weer 'n pos kan kry.”* **Translation:** Oh, it is difficult for us, fortunately we had some money and he received severance pay from the work even though it isn't much. He went to sign for his first UIF. He will probably receive a few rands while he is waiting to get another position.

Participant G: *“Nee, ek het bitter, bitter swaar gekry...hy't ongeskiktheidsdekking, traumadekking, inkomste-beskermers, al daai goed van hom was in plek en nie een van dit het uitbetaal nie...Toe sê ek, dit was nou nog die ergste van die ergste, jy weet, want, toe dag ek nou, joe, weet, jy sit met al hierdie finansiële, mediese kostes...Ek dink alles in alles is dit so drie en 'n half miljoen wat by die medies is daar. Maar omdat ons die medies het, het, het meer as die helfte betaal, maar op drie en 'n half miljoen moet ek vir jou sê daar's seker omtrent 'n goeie R100 000 wat nou, jy weet, dit klink nie baie in vergelyking met R3 miljoen nie, maar R100 000 is, om dit bymekaar te maak is, om al hierdie goedjies te betaal is, is nogal baie.”* **Translation:** No, I really suffered...he has disability cover, trauma cover, income protection, everything was in place but not one paid out...Then I said, that was the worst of the worst, you know, because I thought, gosh, now I'm stuck with all these financial, medical costs...I think all and all, everything was 3.5 million rand according to the medical aid. Because we have the medical aid, they paid more than half, but on 3 and a half million, I must tell you there is about R100 000 which doesn't sound much in comparison to R3 million, but to put R100 000 together to pay everything, is a lot.

Participant H: *“Ek dink een van die moeilikste goed ook is jou finansiële posisie. My vrou het eintlik twee inkomstes gehad. Sy het haar eie eenmansaak gehad, haar eie besigheid wat sy bedryf het en dan het sy skool gehou. En skielik is altwee weg. En skielik sit jy met net een inkomste in die gesin waar sy eintlik haar eie...van twee kante af inkomste gekry het. So dit maak dit moeilik en dit maak dit maak dit ook moeilik vir jou pad vorentoe want jy is nie seker want ons het nog nie 'n uitbetaling van die padongelukke fonds gekry nie. Dit maak dit moeilik vir jou mediese uitgawes. Ons het 'n hospitaalplan, ons het nie 'n vol mediese plan nie so al die terapeute moes ek vir ons het tot Desember so vir 'n jaar en 'n half het sy fisioterapie en arbeidsterapie gekry, maar ons het dit toe nou Desember nie gestop nie, maar die dame wat dit aangebied het, het 'n baba en sy kon nie meer dit in die middag doen nie. So ek sien die sielkundiges, daar is mense wat aanbeveel dat sy nog steeds terapie moet kry, maar*

ons wil dit weer vir haar doen, maar finansieël raak dit baie moeilik. Op 'n stadium raak dit net so dat jy voel net nou ons het gedoen wat ons kan tot op daardie punt en nou moet dit net so bietjie wag en as ons dan kan en daar is 'n uitbetaling, dan sal ons dit wel weer doen...” **Translation:** I think one of the most difficult things is your financial position. My wife had two incomes. She had her own business and she was a teacher. And suddenly both are gone. And suddenly you have only one income in the family where she had her own...income from two sides. So it is difficult, and it complicates things for the future because you are unsure; we haven't received a payment from the road accident fund. It makes it difficult for your medical expenses. We have a hospital plan, not a full medical plan so all therapy I had to, until December she received physiotherapy and occupational therapy but in December, we didn't stop it but the woman had a baby and couldn't give therapy in the afternoons anymore. I see the psychologists, there are people who recommended that she still continues with therapy, I want to do it for her, but financially it is difficult. At one point, it just becomes, you feel that you've done what you can and now it must wait until we have a payment and then we will do it again...

Discussion of sub-theme 5.6

This sub-theme of financial implications was a significant one. Almost every participant commented on how one of the greatest implications of dealing with a family member with head injury was the impact on their finances. It transpired that where the person with head injury was a child, the financial implications were still significant but less so. Where the husband or wife had the TBI, the implications were almost catastrophic because it meant that their income was halved or even quartered. In many instances, families have not made any provision for insurance for disability cover. One participant also stated that finances are her biggest source of concern. Participants were also required to accept financial help from strangers, friends and family. Others weren't as lucky to have any external financial support. The literature supports what participants have shared. Marcelissen (in Williams, 1991:92) states that certain stressors can be exemplified by stress experienced by families post head injury. Each stressor increases the frequency and intensity of reactions to loss. One of the stressors highlighted were finances. Short- and long-term financial issues are reported to be of major concern to the majority of families (Jacobs in Williams, 1991:94). Costs are direct as well as indirect including loss of income, interference with career advancement, and travel expenses. The literature therefore confirms the experienced financial losses described by participants.

3.6.2.6 Theme 6 and sub-themes: Support systems

Theme six: Support systems	Sub-themes: ❖ Family and friends ❖ Religion ❖ Professional support ❖ Employer support
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When a patient with a TBI is discharged from hospital, the family is often expected to cope with the demands that the new adjustment will bring. Having adequate support is very important, it assists with the burden that this new lifestyle brings and also often the family member as caregiver's main support was the person who is now left with a TBI, especially in the case where the patient is a husband or wife. Having a good support network will ease the burden. Support may come from different avenues, but what transpired from the interviews was that family, friends, religion, professional support and support from the family member with TBI's employer was available. Again one of the stressors Marcelissen (in Williams, 1991:92) described, are lack of services. Families of TBI patients do not always have information about their options and choices, and services may be restricted because of geographical location.

- **Sub-theme 6.1: Family and friends**

Participant A: *“Ja van ons familie. Daar is susters in ons familie. Hulle het almal maar ook kom help en ‘n bietjie bygestaan en hand gegee en so aan.”* **Translation:** Yes from our family. There are sisters in our family. They all came to help and gave assistance and so forth.

Participant B: *“Basies maar, ag daar is baie familie ondersteuning en ag ek weet nie.... Nee, daar is nie regtig iemand nie. Elke hier en daar is daar iemand soos my skoonsussie-hulle, my ma het ons ‘n rukkje geondersteun. Sy het geweet hy raak moeilik en daai klas van dinge. Nee, niemand weet regtig nie... Ag weet jy, die ding is daar is sekere dinge wat jy vir sekere mense vertel. Jy sal nooit alles vir een persoon kan vertel nie (crying).”* **Translation:** Basically, but there is a lot of family support and oh I don't know...no there isn't really someone. Every now and again there is someone like my sister in law, my mother assisted us for a while...You know the thing is there are certain things that you will only tell certain people. You will never be able to tell everything to one person (crying).

Participant C: *“Met genade van bo kry mens enige iets reg en met jou familie.” (En waar het die ondersteuning vandaan gekom?) Vriende en my familie. Op hierdie stadium het ons ‘n baie goeie ondersteuning-skema. Ons het eers hier by my ouers gebly, want ek het hulp nodig gehad met hom en veral met my kleintjie. Vriende ook. Moenie my vriende afskryf nie. Hulle het al menigmale, dan daag hulle by my huis op met ‘n sakkie groceries.”* **Translation:** With grace from above and your family you can endure anything. (And where did the support come from?) Friends and family. At this stage, we have a very good support structure, first we lived with my parents because I

needed assistance with him and with my child. My friends as well. Don't forget about my friends. They came to my house many times with a bag full of groceries.

Participant D: *“Ag uhm, ek het altyd soos ek gesê het, ek praat nou maar by die werk en ek pak uit teenoor die een. Almal het my situasie geken so meeste van die mense wat my gesien het of hiernatoe gevra het, hoe gaan dit nou vandag met jou. So almal was eintlik bietjie aan die een kant uhm ook maar bietjie geworried oor my...Jy weet op daai stadium dan bars jy uit in trane en dan voel jy dit is tot hier en nie verder nie, maar ag dan voel jy weer OK daarna.”* **Translation:** Oh uhm, like I said, I speak to people at work and debrief. Everyone knew my situation so most of the people asked me how I was. Everyone was on the one hand a little worried about me...You know at that point you start to cry because you have had enough but then you feel OK after that.

Participant E: *“En onder mekaar het ons mekaar bygestaan en vertroos. My skoonma bly by ons, sy is nou amper 80. Sy was baie ondersteunend vir ons. Al ons vriende wat sms stuur en wat gaan kuier en wat net wil saamry, almal het nie altyd vervoer nie. Dit was net vir my tog iewers het my my kind iewers impak gehad met ‘n goeie hart want so baie mense is bekommerd oor hom.”* **Translation:** We supported and comforted each other. My mother in law lives with us, she is almost 80. She gave us a lot of support. All our friends that sent sms's and that went to visit and wanted a lift, not everyone has transport. For me it was just, somewhere my child had an impact with a good heart because so many people were worried about him.

Participant G: *“...Dieselfde vriendegroep van ons wat ons het, is eintlik nie meer daar nie. Nie dat hulle kwaad is vir ons nie, maar hulle't 'n paar keer gekom om te kom kuier, dan kom hulle agter, OK, maar dis heeltemal anders nou. Xxx sit daar of hy praat glad nie, hy sit net en staar voor hom uit. Dis vir hulle erg, want hulle kan nie eintlik glo dis Xxx nie... Ek meen, mens is nie kwaad vir hulle nie, jy weet, ek gaan, en my vriendinne gaan sit nog en koffie drink, maar die mans voel nie meer gemaklik om daar te kom nie. Hulle het nie geselskap nie, hulle weet ook nie hoe om hom te hanteer nie. En baie van hulle het gesê: Weet jy wat, dit is net te erg vir ons om hom so te sien. Ons wil hom nie so sien nie, ons wil hom eerder onthou soos wat hy was.”*

Translation: ...The same circle of friends that we had is actually not there anymore. Not that they're angry at us, but they came to visit a few times and they realised, OK, things are completely different. Xxx sits there or he is not speaking, he only sits and stares. They found it terrible because they can't believe it is Xxx...I mean we are not angry with them, you know, my friends and I will still sit and drink coffee but the men don't feel comfortable to come anymore. They don't have company; they also don't know how to handle it. Many of them said: You know what; it is just too terrible to see him this way. We don't want to see him; we'd rather remember him the way he was.

Participant H: *“Haar sussie wat langs ons bly het ook baie, sy vat haar saam Cullinan toe, drink bietjie tee. Sy het aangebied sodra ek voel ek kan dit weer bybring om haar te bring vir terapie, jy weet sy het nou dit aangebied. Dit is vir my vreemd, ek weet nie hoekom het sy dit nie in die begin aangebied nie, maar sy het dit nou aangebied toe hulle sien ons doen dit nou nie meer nie. Toe sê sy nou hoekom nou nie, toe sê sy maar sy sal haar nou bring. Nou het ek nie meer die finansies om haar elke week te laat gaan nie...Haar sussie was, ek sal dit nooit vergeet nie. Haar sussie bly direk langs ons ne, direk langs ons, sy was die 17e September met Xxx se verjaarsdag was sy daar ons het haar weer die eerste keer gesien toe het ons haar genooi, nuwejaarsdag. Nou vir iemand wat, daar is 'n deur, daar is 'n muur, wat kan net oorstep, dan vra ek...Dan vra ek is dit ondersteuning? Ek sê mos noudat sy beter is, nou is dit vir my beter...Ja, my familie is almal ver, daar was geen ondersteuning nie. As ek vandag, ek weet dis seker verkeerd, maar as ek vandag vir iemand iets sê oor*

die ongeluk dan sê ek daar was nooit navrae van familie van hoor hier cope julle, kom julle finansiële reg? Kan ons nie finansiële vir julle, al is dit met 'n paar honderd rand, ondersteun nie? Daar is van hulle wat dit regtig kan doen...Jy weet en en mens kan dit seker nie van ander mense vra of dit vereis nie of dis nogal erg ja. Uhm uhm, wat ook maar hartseer vir ons veroorsaak, is mense se reaksie. Mense dink sy het nou herstel, sy is nou gesond en hulle het eintlik vergeet hoe was sy en hoe is sy nou. Sy is nou kort van draad en jy moet haar nou verdra soos sy is. Ek weet nie, ek weet nie wat nie. Dis partykeer vir my baie moeilik, wat sê jy vir familie, wat sê jy vir vriende?"

Translation: Her sister that lives next to us, she also, she took her along to Cullinan, drank some tea. She has now offered when I feel I can afford therapy, she will take her, you know she offered it now. It is strange, I don't know why she didn't offer it in the beginning, but she offered now when they saw we are not taking her anymore. She asked why not now, and then said she will take her. Now I don't have the finances to accommodate therapy once a week...Her sister was, I will never forget it. She lives directly next to us, directly next to us, she was there with Xxx's birthday she was there and we only saw her again when we invited her on New Year's day. Now for someone who, there is a door, a wall, she can just walk over, I'm asking...I'm asking is that support. I said now that she is better, now it is better...Yes my family, everyone is far, there was no support. If I can today, and I know it is probably wrong, but if I can tell someone today about the accident, then I say there was never an inquiry from family whether we're coping, are you coping financially? Can we contribute financially, even if it's only with a hundred rand? There are some of them that can really afford it...You know, but one can probably not expect that of someone else, but yes it is terrible. What also causes heartache for us is people's reaction. People think she's recovered, she is now healthy and they forgot how she was and how she is now. She is short-tempered now and you have to tolerate her as she is. I don't know; I don't know what. At times it is difficult for me, what do you say to family, what do you say to friends?

Discussion of sub-theme 6.1

The quotes above indicate that most participants had the support of family or friends. However, the type of support provided and how participants experienced it varied. One participant stated that she found it difficult to open up and felt that you cannot share everything with one person. Another participant stated that even though they had family living close by, actually next door, months passed without any contact from that family. The quotes indicated the need for support and sharing of responsibility. Sadly not all participants had the luxury of others joining them in taking care of the person with TBI and to provide some form of respite care. Williams (1991:92) stated that in the early stages after the injury, family and friends may still visit often and give abundant support, but as time passes, people may withdraw their support (Bond in Williams, 1991:95). People move on, not knowing how to include the person with a TBI in their lives. This results in the person with a TBI heavily relying on his or her family. Not having anywhere to turn, increases the burden of care that the participants experienced when caring for a family member with a TBI. One participant stated that the friends they had

prior to the accident no longer visits them anymore. Another participant commented on how he found it difficult to respond to family and friends because they did not understand the complexities of his wife's injury. The literature states that all pre-existing relationships have to be re-evaluated as the family have to request assistance and allow for flexibility. At times old relationships cannot be restored and new relationships have to be formed (Williams, 1991:89).

- **Sub-theme 6.2: Religion**

Participant B: *“So uhm, my geloof sê hou vas, dit gaan beter raak.”* **Translation:** So uhm, my faith tells me to hang on, it will get better.

Participant C: *“Met genade van bo kry mens enige iets reg... meeste van alles my geloof het my gedra...”* **Translation:** With grace from above you can manage anything...most of all my faith carried me...

Participant E: *“Ek het maar net elke keer gebid daaroor. Krag gevra, asseblief... Om eerlik te wees van bo af. Die krag kry ek van bo af. Absoluut.”* **Translation:** I prayed about it every time. Asked for strength, please...To be honest from above. My strength I received from above. Absolutely.

Participant F: *“Toe het ons ‘n ruk daar gestaan en toe het ons huis toe gekom en jis daai nag, ek kon nie slaap nie (crying) en soos die meeste van die tyd as ons daar uit gekom het, ons is in die pad en ons ry. Toe het ek opgekyk en gesê dankie Here, dankie dat my kind nog lewe. En dit is maar wat ons gedra het, deur daardie tydperk, dit is maar net die Hemelse Vader... Ag ons predikant, hy staan nog altyd by ons...”* **Translation:** Whe stood there for a while and then came home and gosh, that night I couldn't sleep (crying) and like most times when we walked out and we drove home. I looked up and said, hank you Lord, thank you that my child is still alive. That is what carried us through that period, it is just our heavenly Father...Our pastor, he is still supporting us...

Discussion of sub-theme 6.2

Drenth (1991:51) states that religion plays a very important role in the South African culture and she views it as a system to be reckoned with in dealing with TBI patients and their families. In the interviews with participants, religion was identified as an important source of support. Many participants stated that in a situation where everything was uncertain, they found it comforting to rely on a greater force.

- **Sub-theme 6.3: Professional support**

Participant A: *“Weet jy, ek dink tog in ‘n mate moet die hele familie gemonitor word. En gekyk word of kom hulle reg, cope hulle by die huis. Dan moet bietjie meer gebel word en hoor miskien net gaan kyk hoe gaan dit en so aan.”* **Translation:** I think to an extent, the whole family has to be monitored. And checked if they're managing, are

they coping at home. Then they must be phoned more, and checked how things are going and so forth.

Participant B: *“Uhm, ek weet nie. Ek weet regtig nie want al is daar mense, mens voel nie altyd lus om alles met hulle te deel nie. Mens kan met iemand praat oor sekere dinge en met iemand anders oor ander dinge. As ek iemand gehad het, ek weet nie of dinge anders sou wees nie. (En as dit ‘n professionele persoon was?) Ek weet nie, ek weet regtig nie. Ek kan nie dink dat dit sou anders wees nie. Weet jy dis moeilik as mens in so situasie is want die dae wat jy voel vandag cope ek nie, het jy nie tyd om iemand te bel en te sê vandag cope ek nie. Ek vat dit, as ek een van my dae kry, dan hardloop ek rond en daar is net nie tyd om stil te sit en dink, hoor hier, miskien moet jy iemand te bel en te sê vandag gaan nie goed nie. Sodra jy aan so iets begin dink, dan dink jy maar hoor hierso daai en daai en daai. Dis soos ‘n ‘n ek weet nie dis ‘n... gaan dit regtig help? Ek weet nie. Dis...ek weet nie. Ek is nie daai tipe mens wat gaan sit en gaan sit en dink ek is nie iemand wat sommer iemand gaan opsaal met my probleme nie...Ek het regtig nie nog tyd daarvoor ook nie. Nee ek weet nie, ek glo nie. Vir my persoonlik, maar as ek moet dink miskien iemand wat minder verantwoordelikheid het.”*

Translation: Uhm, I don't know. I really don't know because even though there are people, you don't always feel like discussing everything with them. You can discuss certain things with one person and other things with someone else. If I had someone, I don't know if things would have been different. (And if it was a professional person?) I don't know, I really don't know. I can't think that it would have been different. You know, it is difficult if you're in the situation because there are days that you feel you're not coping, you don't have the time to phone someone to tell them I'm not coping. I take it, if I have one of my days then I run around that there isn't time to sit still and think maybe I should phone someone and tell them today is not a good day. Once you start thinking of that, then you think this and that. It's like, I don't know it's...will it really help? I don't know. It's...I don't know. I'm not that type of person that will burden someone else with my problems...I really don't have time for that. No, I don't know, I don't think so. For me personally, but if I should think maybe someone with fewer responsibilities.

Participant C: *“Ek persoonlik is spyt ek het nie met ‘n professionele persoon op daardie stadium gaan praat nie. Hulle het, die hospitaal het dit vir my aangebied, ek wou nie gehad het nie. Ek het haar een of twee keer gesien, maar ek het, ek het, daar was net nie vir my tyd gewees nie. En vandag is ek spyt ek het nie tyd gemaak nie, want as ek en hy as hy sulke woede uitbarsting kry, dan ons sit so vas dan is ek spyt ek het nie gegaan dat daai persoon vir my kan sê waarom ek so gaan voel nie. Wat om te doen, waar dit vandaan kom. Ja, ek sou sê ek is spyt ek het nie vir professionele hulp gegaan toe nie.*

Translation: I personally regret not speaking to a professional person at that time. They, the hospital offered, I didn't want to. I saw her once or twice, but there just wasn't time. Today I regret that I didn't make the time, because when he has anger outbursts and we fight then I regret that I didn't go, so that that person can tell me why I'll feel like this. What to do, where it comes from. Yes, I would say I regret that I didn't go for professional help then.

Participant G: *“Ek was so drie keer by haar en toe besef ek dis nie die informasie wat ek, dis, daar was niks fout met haar nie, maar ek meen, dis, sy het vir my gesê; Jy weet wat, sy dink my situasie is so erg dat uhm, ek sal maar moet ‘n besluit maak, dat ek maar liefste my kinders vat en dis ook nie my skuld dat hy in die ongeluk was nie. Weet, dit was vir my baie moeilik, want ek het op daardie stadium gedog, nee, weet jy wat, ek sal maar ‘fight’ tot die bitter einde toe, jy weet? Ek is nou nie, ek wil nou nie uitstap as ‘n ‘loser’ en sê, weet jy wat, ek sal nog bietjie vasbyt. Ek het toe intussen*

nou by iemand anderste uitgekom wat meer konkreet en reguit was. Ek dink in my situasie sou ek sê, uhm, verseker moet jy gaan vir so iets, want ek dink die trauma, dit, dit kom maar weet, die trauma alleen wat jy beleef, die goed wat jy alleen daar gesien het, nè, is klaar erg op die onderbewussyn. Nou's dit nog hierdie pad, so teen die tyd wat jy eintlik baie krag moet hê wanneer hy huis toe kom, is jy eintlik alreeds emosioneel ge-'drain', was jy alreeds deur hierdie verskriklike emosionele ding en nou lê vir jou 'n nog erger pad voor wat jy met hom moet deel. En dis daar waar die skaaltjie bietjie van balans af gaan.” **Translation:** I went to her for three sessions and then I realised it is not the information that I, there was nothing wrong with her, but I mean she told me you know what, she thinks my situation is so terrible that I have to make a decision, to rather take my children and it is not my fault that he was in the accident. You know, I found it very difficult because at that time I thought, no you know what, I will fight until the end, you know? I don't want to walk out as a loser and said, I will carry on. In the mean time, I found someone else who is more concrete and to the point. I think in my situation, I would say you have to go for something like that because the trauma, it comes, the trauma that you experience, everything that you saw is terrible on the subconscious. Now it is this road so by the time you need all your strength when he comes home, you're already emotionally drained, you've already been through this highly emotional thing and now there is an even worse road ahead that you must share with him. It is there where the scale tips off balance.

Discussion of sub-theme 6.3

The literature indicates that many TBI patients seek counselling after hospitalisation and rehabilitation. This is either to assist with readjustment to life after the injury or for other mental health issues (Patterson and Staton 2009:149). The interviews with participants did not indicate that many of the family members sought professional support, in fact only one participant indicated that she received professional support after her husbands' injury. Three participants indicated that they had a need for professional support post discharge from rehabilitation, but that it was not available. Reasons for it not being available was a lack of time and probably finances. Finances weren't explicitly given as a reason, but when financial implications in theme five is taken into consideration, it makes sense that there were no financial resources for professional support. Currently in the Pretoria region, there are very few professional supportive agencies available specifically for TBI. There is also no formal respite care available for family members with TBI. The one participant, who indicated that she did go for professional support, stated that she had to find an alternative professional as the first person did not fully understand the complexities of her husband's injury.

- **Sub-theme 6.4: Employer support**

Participant A: *“Sy werk wou nie sy geld vir ons gee nie, want ons moet uh uh kuratorskap aanstel. Daar het ons probleme gehad. Orals was net probleme gewees.*

En hoe meer ek vir hulle verduidelik ek het nie die finansies om hom nou nog in 'n plek te sit nie, ek het nou al klaar my ma oorgevat hoe meer druk het hulle op ons."

Translation: His work did not want to give the money to us, we had to uh uh get curatorship. There we had problems, everywhere was just problems. And the more I explain I do not have the money to put that in place. I've taken over my mother as well, the more pressure they put on us.

Participant D: *"Jy weet sy het nog haar volle salaris gekry in hierdie tyd wat sy nou af was, so sy was baie gelukkig."* **Translation:** You know she still received her full salary in this time that she was off, she was very fortunate.

Participant F: *"Hulle het nou vir hom gesê daarso hulle retrench hom nou want hy kan nie die werk doen wat hy vantevore gedoen het nie... .En daar was maar altyd sulke haakplekkies en hy was nog in die hospitaal toe het hy al gesê hy wil hom retrench. So daar moet mens maar bietjie besef en ek ek dink dit is wat gebeur het ook in die feit dat hulle sê hy vergeet. Ek dink dit is 'n kwessie want hulle het hom al meer gedruk en gedruk. Sy baas het vir hom gesê ek gaan jou laat werk tot jy huil. Ja daar was geen menslikheid nie. Aan hulle kant nie. Geen deernis nie."* **Translation:** They told him they are retrenching him now because he can't do the work that he did before...there was always hiccups, he was still in hospital when they told him they want to retrench him. One has to realise and I think that is what happened and that they say he forgets. I think it is an issue because they've put pressure on him. His boss told him I will let you work until you cry. Yes there was no humanity from their side. No compassion.

Discussion of sub-theme 6.4

The quotes above indicate that family members of people with TBI need support from the employer of the person with TBI. Of all the participants, only one indicated that she received her salary throughout her sick-leave. Other participants indicated that they experienced a lack of support and compassion from employers for what they were going through. As financial implications of TBI were identified as a major stressor, the researcher can fully understand the need for support from employers. If support from employers is in place, it will be one less thing for family members to be concerned about. According to Douglas and Spellacy in Webster, Daisley and King (1999:596) social support has been identified as the most important factor for family functioning when dealing with brain injury. The researcher couldn't find reference to employers specifically.

3.6.2.7 Theme 7 and sub-themes: Effects of TBI

<p>Theme seven: Effects of TBI</p>	<p>Sub-themes:</p> <ul style="list-style-type: none"> ❖ Memory ❖ Laziness ❖ Lack of insight ❖ Changed person
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	<ul style="list-style-type: none"> ❖ Aggression/anger/rudeness ❖ Social immaturity ❖ Selfishness
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According to the US National Institutes of Health (in Khan *et al.*, 2003:291) it is the “complex neurobehavioral sequelae that produce the greatest disruption to quality of life. Cognitive and behavioural changes, difficulties maintaining personal relationships and coping with school and work are reported by survivors as more disabling than any residual physical deficits”. The literature further states that: People with head injuries and their families tend to underestimate the extent of cognitive, psycho-social and emotional dysfunction (Kneipp 1991:165). All of the effects of TBI that were identified in this theme was cognitive, psychosocial or emotional and none due to the physical disability.

- **Sub-theme 7.1: Memory**

Participant B: *“Baie keer sal jy met hom dinge praat en dan lyk dit of hy regtig verstaan en môre as jy weer met hom praat dan is dit soos waarvan praat jy nou? Dit is baie frustrerend, want ek bedoel voor die ongeluk was dit nie so nie.”* **Translation:** Many times you will speak to him and it looks as if he understands and tomorrow when you speak to him again then it is like what are you talking about? It is really frustrating because I mean before the accident it wasn’t like that.

Participant C: *“Hy spot altyd en sê sy breins kom reg. Hy sal byvoorbeeld vanaand by die huis kom en sê, my skat, ek het vandag onthou hoe om dit en dit te doen.”* **Translation:** He is always joking and saying his brains are improving. He will come home and for example tell me; today I remembered how to do this and that.

Participant D: *“In die begin het sy ons glad nie geken nie. Sy het vir my gesê juffrou. Sy het Engels begin praat wat ons nooit praat nie, ons is mos Afrikaans. So sy het in die begin heeltyd Engels gepraat en as ek daar kom dan wil sy weet nou maar juffrou nou wat kom soek jy nou hier? Ek moes oor en oor vir haar sê, Xxx ons praat Afrikaans. Ek is jou suster, ek is nie jou juffrou nie...In die begin was dit vir haar moeilik, sy het niks geken nie. Al die goed was vreemd in haar kaste, sy sal byvoorbeeld ‘n radio daar sien staan, dan sê sy vir my, sjoe maar dis nie haar goed nie... Sy het my, jy weet veral met die vergeet. Sy het eendag, ons het gery toe sit sy haar beursie en dit is nadat ek al hoeveel keer gesê het Xxx los jou beursie by die huis jy gaan hom êrens laat lê en dan weet ons nie waar is hy nie. Al jou kaarte, bankkaarte is in daai beursie. Nee, sy wil die beursie saamhê. Toe ons toe nou by die huis ry, toe sit sy die beursie op die kar se dak neer.”* **Translation:** In the beginning she didn’t know us at all. She called me miss. She spoke English and we never do, we are Afrikaans. So in the beginning, she always spoke English and when I came to the hospital she asked me, “Miss, what are you doing here?” I had to tell her over and over again, Xxx we speak Afrikaans. I am your sister, not your teacher... In the beginning it was difficult for her, she didn’t remember anything. Everything in her cupboard was unfamiliar to her, she would for example see a radio there and say to me, *gosh*, this is not my stuff...She gets me especially with the forgetting. One day,

when we left in the car she left her purse, and that is after I told her numerous times leave your purse at home because you're going to let it lie somewhere, and we will not know where it is. All your cards and banking cards are in that purse. No she wants to take it along. When we left, she forgot it on the roof of the car.

Participant F: *“So al wat ek kan agterkom en wat hulle by die werk ook sê is hy vergeet bietjie.”* **Translation:** So all that I notice and what they say at his work is that he forgets a little.

Participant G: *“Toe't ons agtergekom hy kan nie onthou nie. En daar't mense by hom gekom: Hallo Xxx, en dan't hy nie geweet wie dit is nie. Toe was dit soos half 'n groot skok, maar toe dink ek, weet jy wat; mens het nooit so daaraan gedink nie. Mens het heelyd net gehoop hierdie liggaam kom net hier uit en hy kan net opstaan uit die koma uit en kan loop, en toe kom 'n ou met 'n skok agter, OK, weet jy wat, nou kan hy skielik nie onthou nie.”* **Translation:** Then we realised he can't remember. And people came: Hallo Xxx, and he didn't know who they were. That was a big shock, but then I thought, you know what, you never thought of it that way. You hoped that his body would come out of this, if he could just stand up from the coma and walk and then you realised with a shock, OK, you know what, suddenly he can't remember.

Participant H: *“Sy vergeet baie met ander woorde as hulle vir haar 'n opdrag of iets vra, gaan sy vergeet...Ek meen ons baklei nie met haar daaroor nie, ons raas nie met haar daaroor nie...”* **Translation:** She forgets a lot, in other words, if they give her an instruction or ask her something, she will forget. I mean, we don't fight with her...

Discussion of sub-theme 7.1

Cognitive problems after a traumatic brain injury can include limitations in memory, attention, orientation, problem-solving abilities, hand-eye coordination, judgement, insight, reasoning and multitasking (Uomoto & Uomoto, [sa]:1; Struchen & Clark, 2007:19-21; Wikipedia, sv 'traumatic brain injury' and Quintana, 1997:201). The quotes above reflect the participants' frustration with their family members' memory impairments. Participants state that they were not completely prepared for the cognitive impairments because they were so happy when the person emerged from the coma and they then realised that, even though the body survived, there were other implications as well. Participants also commented on how shocked they were when they first realised that the person could not remember. One participant commented on how difficult it was because her family member had forgotten that she is Afrikaans and only spoke English. Memory impairments have also led to one of the participants' family member being retrenched from his work. Another frustration was that children couldn't trust their mother due to her memory impairments. As can clearly be seen, the effect of memory impairment implies great frustrations for family members.

• **Sub-theme 7.2: Laziness**

Participant B: *“Hy slaap nou meer. Ek wil amper sê hy is nou ‘n lui mens, wat hy nie voorheen was nie... Maar om vir hom te sê, Xxx asb spuit net die tuin nat, Xxx, asb spuit net die tuin nat. Ag, eintlik was so ook voor die ongeluk. Hy’s net uhm, ek kan eintlik nie sê lui nie. Ek gaan sê lui want sy werk was alles gewees en die huiswerk was nog nooit ‘n prioriteit by hom gewees nie en nou is die werk nie meer daar nie so die prioriteit is ook nie oorgeskuif na die huis toe nie. So jy kan ook nie...lui is seker nie die regte woord nie, maar dit is nou maar die woord om dit te beskryf.”* **Translation:** He is sleeping more. I want to say he’s become lazy, which he wasn’t before...But to tell him, Xxx please water the garden, Xxx please water the garden. Actually he was like that before the accident. He is just, I can’t really say lazy. I’m going to say lazy because before his work was everything and housework has never been a priority for him. Now his work isn’t there anymore and the priority did not shift to the house. So you can’t...lazy is probably not the right word, but it is the word to describe him now.

Participant C: *“Hy het ‘n baie lui mens geword, baie lui. Uhm, ek moet self wasgoed was, self skottelgoed was, ek moet vir hom stryk.”* **Translation:** He became a very lazy person, very lazy. Uhm, I have to do the washing myself, wash dishes myself and I have to iron for him.

Participant D: *“So in die eerste plek het dit haar lui gemaak... In die begin was sy vreeslik lui om kos te maak hoor. Glad nie, glad nie belang gestel om kos te maak nie...Die volgende dag toe gee Bbb vir haar ‘n lêer, en sê, hoor hier, jy moet nou hierdie papiere bietjie agter mekaar sit en sal jy vir my bietjie die blaadjies nommer en so. Uhm toe sê Bbb vir haar wil jy dit doen? Toe sê sy nee. Toe sê ek vir Bbb nee julle moet nie vir haar vra wil sy dit doen nie. Sê vir haar doen dit, want ek by die huis doen dieselfde. As ek haar moet vra gaan jy my help huis skoonmaak dan gaan sy nie. Ek moet vir haar sê hoor hier Xxx asseblief kom help my.”* **Translation:** So in the first place, it made her lazy...In the beginning she was very lazy to cook. She was not interested at all to make any food...The next day Bbb gave her a file and said will you organise the papers and number the pages? She said no. I told Bbb no, you mustn’t ask her, tell her to do it. At home it is the same. If I should ask her to help me tidy the house, she won’t. I have to tell her, Xxx please come and help me.

Participant E: *“En hy is nie ‘n kind wat sy goed net rondgooi nie. Hy sal rondgooi, maar as jy hom vasvat dan gaan gaan hy daaroor dink en paar keer daaraan werk en so. En hy het net neergegooi. (So jy sê hy was bietjie meer slordig gewees?) Ja, hy was bietjie meer slordig gewees.”* **Translation:** And he is not a child who will throw his things around. He will but if you speak to him about it, he will think about it and work on it. And he threw his things around. (So you are saying he was sloppier?) Yes, he was a bit sloppier.

Participant G: *“Wat ek net agterkom, hulle raak lui. Want, uhm, die moment as hulle agterkom hulle kan jou intrek, gaan hulle half misbruik van jou maak die heeltyd. En hoe meer jy vir hulle doen, hoe minder wil hulle doen.”* **Translation:** What I realised, is they become lazy. Uhm, the moment that they realise they can involve you, they will abuse you the whole time. And the more you do for them, the less they will do.

Participant H: *“Sy het ‘n kan-nie-worry houding en as ek daarvan sê, dan sê ek sy worry nie hoe dit in die huis lyk nie. Sy worry nie of daar kos is vir die huis nie, sy maak nie kos eintlik baie nie. Soos nou vandag byvoorbeeld: Ek was nou by die huis, haar vinnig by die huis gaan kry. Sy sal geen kos maak nie, daar is niks gemaak nie. So dit is vir ons as gesinslede erg, jy weet? Die kinders is partykeer erg moedeloos. Hulle kom honger van die skool af, het mamma nie kos gemaak nie? Nee, ek was moeg vandag sal sy byvoorbeeld net sê.”* **Translation:** She has a don’t-care attitude and what

I mean is she doesn't worry what the house looks like. She doesn't care if there's food in the house, she doesn't actually cook a lot. Like today for example: I was at home to pick her up. She won't make any food, nothing has been made. So for us as family members it is terrible. The children become discouraged at times. They come home from school, hungry. Mommy, didn't you prepare any food for us? No, I was tired today, is what she would for example answer.

Discussion of sub-theme 7.2

The sub-theme of laziness has been a significant one. Almost all of the participants commented that they found their family member with a TBI to be lazy. When studying the literature, the researcher found the following: Some persons with TBI lack appropriate initiation to attempt tasks. Problems with initiation can often be misinterpreted as laziness or as non-compliance. This may accompany particular patterns of neurological damage that disrupt the connection between limbic motivational inputs and the cognitive and motor components of action. These deficits are found to have great effects on living independently and psychosocial functioning (Delisa & Gans in Burns, 2008c:162; Uomoto & Uomoto, [sa]:1 & Struchen and Clark, 2007:22). It is difficult to say if the participants were able to distinguish between lack of initiation and laziness. The fact that remains that it has a profound effect on family members. They were struggling with what they perceived as laziness. The literature study didn't reveal any other significant information with regards to perceived laziness.

- **Sub-theme 7.3: Lack of insight**

Participant C: *“En hy wou eers nie verstaan dat ... hy woede uitbarstings kry, dan stry hy. Môre, oormôre dan praat jy met hom daaroor dan stry hy, maar dis asof hy nou begin besef dat ek nie praat nie, jy weet nonsens praat nie, dat ek die waarheid praat.”*

Translation: At first he didn't want to understand that he gets anger outbursts – he'll deny it. Tomorrow, when you speak to him, he will deny it, but it is as if he is starting to understand that I'm not lying, I'm speaking the truth.

Participant D: *“Hoor hier, die moeilikste vir my is, sy krap vir my vreeslik baie om nou dat sy begin werk. Want sy sal my bel en dan sal ek vir haar vra wat het jy vandag gedoen? Wat het jy geleer vandag? Nee ek speel tv-games. Dan sê ek vir haar nee Xxx, dit is nie wat jou gaan help nie. Jy moet opstaan, vir die mense vra is daar iets wat ek kan doen in hierdie kantoor? Jy kan nie net met daai houding kom en sê ek speel nou tv games nie.”*

Translation: Listen, the most difficult is that she upsets me now that she has started working. She'll phone me and I would ask her what did you do today? What did you learn? No I'm playing TV-games. Then I'll tell her, no Xxx, that is not going to help you. You must get up and ask the people, is there something that I can do? You can't come with that attitude and say I'm playing TV-games.

Participant G: *“Dit was net daai gevoel; hy't eintlik so half 'n haat gehad teenoor my oor wat met hom gebeur het, want hy sal baie keer nog sê maar ek het hom daar ingedruk vir 4 maande. En dan sal ek vir hom sê maar weet jy, besef jy regtig hoe seer*

jy...? Dan sê hy hy weet, dan sê ek, OK, nou wat sou jy gedoen het as jy in my skoene was? Toe sê hy, nee, ons moes hom net daar op die pad gelos het, want hy sou self reggekom het. So nou kom daai besef en insig en, hy verstaan nie eintlik, ek dink nie hulle besef regtig waardeur hulle is nie – hoe erg dit was nie.” **Translation:** It was just that feeling, he hated me for what had happened to him because many times he would say I put him there for four months. Then I’ll say to him, do you realise how badly you were hurt...? Then he’ll say he knows, that I’ll ask him, OK, what would you have done if you were in my shoes? He said I should have left him there on the road because he would have recovered by himself. Then I realised, he doesn’t really understand, I don’t think they realise what they’ve been through – how bad it really was.

Participant H: *“Dit is ‘n ander groot ding, sy vergeet soms om haar medikasie te neem haar anti-depressant en dan is dit, dan is dit moeilikheid in die huis.”* **Translation:** It is another big thing, she forgets to take her medication, her anti-depressant and then there is trouble in our home.

Discussion of sub-theme 7.3

From the quotes above, it appears that there are different components in lack of insight. One is lack of insight with regards to limitations and the other is just lack of insight into what appropriate behaviour is. Participants stated that they found the lack of insight difficult to handle, especially if the person with TBI provided resistance to them. One participant commented on how difficult it is when the person with TBI does not take his or her medication correctly. The literature study revealed that a lack of insight into limitations (including behavioural difficulties) makes intervention difficult (Burns, 2008c:162). According to Burns (2008c:163) persons with TBI are usually less aware of cognitive and behavioural deficits than of physical deficits. Some may be aware of deficits but show poor understanding of the consequences. This also transpired during the interviews: the person with a TBI seemed unaware of the consequences of certain actions and this made it difficult for participants to have to cope with it on a daily basis.

- **Sub-theme 7.4: Changed person**

Participant B: *“Nee, Xxx was baie verdraagsaam. Hy sou net stil gebly het en aangegaan het. En net op ‘n dag sou hy gesê het nou het hy genoeg gehad. Nee, daai gedeelte het baie verander... (Wat is nog anders?) Dis maar ‘n breinbesering. Hy is totaal anders. Hy is nie meer wat hy was nie.”* **Translation:** No, Xxx used to be very patient. He would just keep quiet and go on. And one day he would say now he’s had enough. No, that part really changed... (What else changed?) It is a head injury. He is totally different. He isn’t what he used to be.

Participant C: *“Hy is net my man met ‘n persoonlikheid, die is nie my man se persoonlikheid nie... Dat hulle persoonlikhede heeltemal verander. Uhm, hy is ‘n ander mens.”* **Translation:** He is just a man with a personality, not my husband’s personality...That their personalities changed completely. Uhm, he is a different person.

Participant D: “Kom ek sê jou sy was nooit so nie. Sy was nooit ‘n lui persoon nie. Sy was nooit ‘n suinige persoon nie. Ek dink en soos almal nou met my praat haar vriende en sulke goed, weet Xxx was nie so nie.” **Translation:** She has never been this way. She was never a lazy person. And as everyone said to me, her friends and so on, know Xxx wasn’t like that.

Participant F: “So dit is al en dan kom ek agter weet jy dis asof sy persoonlikheid vir my mooier geword het. Kyk hy was nooit ‘n harde mense nie en hy het nooit, hy kon nooit met my regtig lelik gepraat of so nie. Dis vir my asof hy ‘n meer liefdevolle kind geword het, regtig. En hulle het vir ons gesê baie keer met sulke bipolarêre mense of pasiënte is dat hulle geaardhede kan omswaai vir die verkeerde. En ek sê net dankie ,dankie dankie, elke dag. Dat dit vir my na die ander kant toe geswaai het en nie na die lelike kant toe nie.” **Translation:** So it’s like his personality became more agreeable. Look, he has never been a hard person and he couldn’t really be nasty to me. It is just as if he is now a more loving child, really. They told us that bipolar people or patients’ personality can turn for the worst. I just want to say thank you, thank you that it swung to the other side and not to the nasty side.

Participant G: “En toe’t hy begin met hierdie verskriklike aggressie, weet, in Trauma ICU al. Weet, hy’t pype uitgeruk, en jy kon, naderhand kon ons net nie naby hom kom nie, want ek het...naderhand moes ek daar wegbly. Dat ek vir my sê, weet jy wat, dalk moet ek net nie soontoe kom nie, want dit het my in my siel in ontstel, want ek meen dis nie die mens wat ek ken nie. En hy’t nooit ‘excited’ geraak oor niks nie, ek het altyd gewens hy kon bietjie excited raak! (Laughing). En nou ewe skielik, nè, is dit absoluut die teenoorgestelde...dit het my baie gevang toe, as jy nou eintlik besef, weet jy, jy’t nou gedoen wat jy kan doen, maar mens moet die realiteit besef. Daar is skade – hy is nie dieselfde mens nie.” **Translation:** And then he started with this terrible aggression, know, from Trauma ICU. Know, he pulled out pipes and you could eventually not even come close to him, because I...eventually I stayed away. I told myself, maybe I shouldn’t go because it upsets me in my soul, I mean it wasn’t the person that I knew. He never got excited about anything, I often wished he could get more excited! (Laughing). And now all of a sudden, it is absolutely the opposite...it got to me if you realise, know, you did what you could but you have to accept the reality. There is damage, he is not the same person.

Participant H: “Dis hartseer aan die een kant want dit is nie die mens wat jy geken het nie. Sy is anders... Daar is gedragsveranderinge. Byvoorbeeld sy het ‘n kannie-worry houding. Sy was altyd vreeslik presies. Jy weet, vreeslik netjies op haarself. Sy sal byvoorbeeld verkeerd aantrek, as ek dit so kan uitdruk. Sal sal half slordig voorkom waar ons gewoon was sy was baie netjies en baie presies op haarself en haar hare en goed en ons moet haar herinner: was jou hare en goed, of hoor hier, doen jou hare; jy kan nie so gaan nie, jy weet, en tot nou na twee jaar dat ek en die kinders veral ek vir haar sê luister hier is jou klere, ek sit dit uit, trek môre dit aan. Want ons is bang sy kom in verkeerde drag, as ons dit so kan noem, by soos vandag se afspraak uit.”

Translation: It is sad on the one hand, because it is not the person that you knew. She is different...there are behavioural changes. For example. she has a couldn’t-care-less attitude. She has always been precise, you know, very neat on herself. She will dress inappropriately, if I can put it like that. She will look half sloppy where we were used her always looking neat and her hair and stuff; we have to remind her to wash it or do your hair, you can’t go like that. You know it has been two years after the accident and the children and I have to tell her, here are your clothes, I’ve put them out for you, and tomorrow you must wear them. We are scared that if we don’t do it, she will put something on that is inappropriate, for like today’s doctor’s appointment.

Discussion of sub-theme 7.4

After family members realise that their loved one with a TBI will live, they feel so relieved that the person is still alive that they often don't see all that has changed,. Usually throughout rehabilitation, they are still not fully aware of all the changes and it is mostly in a protected environment. Only when family members take the person with a head injury home, they realise the full extent of the injuries. On this theme participants commented how they realised that the person was different, they spoke about 'a changed person'. One participant commented on how sad he felt when he realised that his wife was not the same person anymore. Another participant commented on how it had upset her in her soul when she experienced the aggression. (Aggression is part of theme five). According to Uomoto & Uomoto, ([sa]:2), "emotional and behavioural changes will often be very stressful to family members". One participant commented on how her family member (who has bipolar disorder) seemed nicer to her and how relieved she felt that the change was positive and not negative. To conclude this sub-theme, families need to get in touch with each other from the beginning as TBI brings with it in many instances a completely new person, whether the changes are positive or negative.

- **Sub-theme 7.5: Aggression/anger/rudeness**

Participant C: *"Baie woede-uitbarstings... Sy woede-uitbarstings is vir my iets vreesliks. Dis, dis baie erg. Skree en vloek as hy nie sy sin kry nie. Skree en vloek as hy sukkel. Hy het nou die dag die DVD-masjien, ons het die DVD ingesit en die CD het afgeval. Hy het die DVD-masjien oopgemaak toe sê die ou vir hom toe kry hy dit nie terug nie. Drie minute toe gooi hy daai DVD dat daai DVD flenters trek."* **Translation:** Many anger outbursts...His anger outbursts are something terrible. It is awful. Screams and swears if he doesn't get his way. The other day, we put a DVD in the DVD players and the CD fell off. He opened the DVD player but couldn't put it back together again. Three minutes and he threw it that it broke.

Participant D: *"Sy, sy het skielik, ons het vir haar 'n teddiebeertjie gekoop, sulke klein teddiebeertjies in ICU. Daar was 'n spesifieke enetjie wat sy nou gelike het, so hierdie ding was heeldyd in die bed en goed. Sy sy sy as jy daar kom party dae wou sy glad nie met my praat nie. Dan het sy weggedraai, dan het sy die kant toe gelê...Ek gaan nou weer die meitjie laat loop want jy baklei heeldag meer met die ousie en die ousie voel bang vir jou en aan die ander kant sy weet nie wanneer raak jy aggressief en die tipe goed nie. Uhm, jy sien die ousie het een of twee keer haar babatjie saamgebring. Die oomblik as die babatjie huil, dan kon sy dit nie hanteer nie. Dan sou sy byvoorbeeld sommer vir die meitjie gesê het, hoor hier loop net, gaan net weg jy weet. Toe het die ousie begin skrik en dalk raak sy nou van haar verstand af en rand my aand of iets. Ag ja, en sy het haar af en toe vreeslik vererg vir my ook jy weet."* **Translation:** Suddenly

she, we bought her a teddy bear, a small one in ICU. There was one specific one that was in her bed the whole time. She, she, she when you arrived there - sometimes she didn't want to speak to me. Then she turned away and moved to the side...I am going to let the domestic worker go because you fight with her the whole time and she is scared of you and on the other hand, she doesn't know when you become aggressive and that type of stuff. Uhm, you see the domestic worker brought her baby along once or twice, and when she cried, she couldn't tolerate it. She would then for example, say to her, just leave, just go away, you know? Then the domestic worker got a fright and maybe she thought, Xxx will lose her mind and attack me. Yes she also became annoyed with me, you know?

Participant G: *“Dan kom jy daar aan en dan is hy amper so half wreed teenoor my, jy weet. Hy's ongeskik met jou en hy, weet, is aggressief en hy wil hier uit. En, en nou begin hy verwyte gooi en hy begin vir jou te sê, so ja, dan is dit nou nogal, jy weet, dan stap jy nou met 'n swaar hart daar weg. Jy weet, party dae, het ek gedink, jy weet, is dit nou die moeite werd om nou so ver te ry om nou daar te kom en jy't hierdie prentjie wat jy vorm en dan's dit eintlik erger as jy daar kom... En wat ek nogal gedoen het wat met hom baie interessant was, ek het oor sy aggressie byvoorbeeld, uhm, uhm, toe ons nou teruggekom het was dit een van die ergste, jy weet hy't alles stuk-...al wat 'n glaspot in my huis is, het hy eendag stukkend gegooi. Daar was 'n paar kere wat ek regtig die kinders moes vat, hulle 12-uur in die nag in die kar laai, en ek moes ry.”*

Translation: Then you arrive there and he is cruel towards me you know? He is rude with you and he, you know, is aggressive and wants to get out. And now, he is starting to lay blame and tells you, uhm yes, then go you away with a heavy heart. Some days I thought, is it really worth coming so far, and to go away and you have this picture in your mind and then it is even worse when you arrive...What I also did, uhm when we got home, that was the worst you know, he broke every glass vase in my home. There were times when I had to take the children 12 o'clock at night, put them in the car and had to leave.

Participant H: *“Uhm, ag weet jy, sy is baie meer aggressief nou. Baie meer aggressie. As jy haar dan kwaad maak. Ja, partykeer is mens in die verleentheid, sy uh as sy haar vererg sal sy op die pad vir die mense die vinger wys al bestuur ek en ek voel daai ou het nou verkeerd bestuur, dan sal sy vir hom skree en sy sal vir hom vinger wys, so ons moet haar altyd bedaar en kalmeer en weet? Sy was baie kwaai en lelik met ons. Weet ek sou sê “Sê hallo Xxx”, dan sal sy sê moenie met daai stemtoon kom nie, ek ken daai skynheilige stemtoon of wat ook al” en dan sal sy, uhm sy het ons vreeslik gego as ons iets sê. Sy was baie aggressief, jy weet. Ons het nie met haar gesukkel nie, jy weet.”*

Translation: Uhm, you know she is much more aggressive now. Much more aggressive. If you make her angry. Yes, at times you are embarrassed, if she becomes angry then she will show drivers on the road the finger, even though I am driving and felt that guy made a mistake, the she will scream at him and show him the finger. We always have to calm her down and know? She was very rude and angry with us. Know I will say hallo Xxx, then she will say don't come with that tone of voice, I know that hypocritical tone of voice or whatever, and challenges us when we said something. She was very aggressive, you know? We didn't mess with her.

Discussion of sub-theme 7.5

This sub-theme was a significant one. Participants took a lot of time describing how their family member was rude to them, showed aggressive behaviour and

demonstrated their anger. This makes a difficult time, even more difficult because the participants had to tolerate rude, and as one participant said, cruel behaviour for long periods. According to Degeneffe (2001) psychosocial changes after a TBI can impact both behaviour (including impulsivity, agitation, lability, withdrawal and disinhibition) and personality (including depression, anger, denial, passivity, dependency and low self-esteem). TBI can also lead to agitation and aggression and it is found to be part of the clinical picture of a person who is emerging from a coma (according to the Rancho Los Amigo levels of cognitive functioning). The frontal regions that are often injured in TBI are believed to play an important role in the inhibition of impulse and inappropriate responses. Many patients never fully regain control over volatile or disinhibited behaviours. This can present itself mildly as irritability or severe as outbursts of physical or verbal aggression (Burns, 2008c:162). While violent behaviour is rare, it can occur. Mostly, people will feel angered more easily and be more prone to verbal outbursts (Struchen & Clark, 2007:23). Participants described violent verbal outbursts as terrible and at times difficult to cope with.

- **Sub-theme 7.6: Social immaturity**

Participant B: *“Hy weet nie baie keer waar om die lyn te trek as dit kom by...uhm om ‘n voorbeeld te vat Xxx (child). Sy is in haar tienerstadium so sy wip haar partykeer dan kan hy baie lelik raak met haar. “Jy beter jou houding regkry” en sulke klas van dinge. So, dit is, hy is maar soos ‘n gewonde mens, as mens dit so kan stel. Hy kry maar sy dae waar hy voel almal irriteer hom, dan is hy geïrriteerd. Hy kry sy dae wat hy voel hy wil met niemand praat nie; dan wil hy alleen wees en dan moet niemand met hom praat nie.”* **Translation:** Many times, he doesn’t know when to stop if it comes to...uhm to use an example Xxx (child). She is an adolescent, so she takes offence and then he is awful with her. You better get your attitude straight, and that type of thing. So he is like a wounded person, if you can call it that. He gets days that he feels everyone irritates him, and then he is irritated. He gets days when he doesn’t want to speak to anyone and wants to be alone and then no-one should speak to him.

Participant D: *“So jy kan nie elke dag sien hoe is sy as jy daar gaan kom nie. Maar kom jy môre daar dan gryp sy die teddiebeer en druk sy hom in die bed.”* **Translation:** You can’t see how she will be when you arrive. If you arrive there tomorrow, she grabs her teddy bear and puts him in her bed.

Participant E: *“Maar hy sal byvoorbeeld as ek hom vasvat oor die rook dan sal hy sê ja, maar ons begin hom skuld gee vir dinge ensovoorts.”* **Translation:** He will, for example, if I confront him about smoking, then he’ll say we are blaming him for certain things and so forth.

Discussion of sub-theme 7.6

Social immaturity is one additional thing that participants have to deal with. One participant stated that she finds it difficult because her husband still wants to discipline their child but his behaviour is socially immature. People with TBI that show signs of immaturity also lack the insight to understand their behaviour and it is difficult for family members to endure this on a daily basis. Ylvisaker (in Drenth, 1991:38) names the following personality changes: apathy, decreased motivation, emotional lability, irritability, depression and lack of initiation, disinhibition, low frustration tolerance, increased or decreased reaction of sexual impulses and social immaturity.

- **Sub-theme 7.7: Selfishness**

Participant B: *“Hy verstaan dat die kinders kom eerste, so baie keer dan word ek kwaad vir hom, want dan soek hy nou eerste plek en die kinders moet maar wag vir hulle beurt en as hulle ooit ‘n beurt kry.”* **Translation:** He understands that the children come first but many times I will become angry with him because he wants the first place and the children must wait for their turn, if they ever get a turn.

Participant D: *“Jy uhm kom ek sê jou ek dink sy het agtergekom luister almal doen vir my alles, want op daai stadium het jy haar so jammer gekry dat jy nie eintlik wil hê sy moet iets doen nie, jy doen dit maar vir haar, jy weet. Sy kon nog nie met haar geld gewerk het nie, so ek sal haar geld gaan trek en ek sal koop wat sy nodig het en sulke goed. Toe kom sy nou agter maar almal kry my nou jammer en almal doen alles vir my. En ek dink dan vat hulle op ‘n stadium bietjie advantage daarvan. Hoor hier as ek nou gepraat het, dan moet jy nou spring. En as jy dit nou nie gaan doen nie dan is die hel los... Jy sal byvoorbeeld vir haar sê, “Hoor hier, Xxx, ons is nou hier in Checkers, koop nou wat jy dink jy nodig het en waarvoor jy lus is sodat jy nie in die week honger ly nie. Jy het nou genoeg geld gespaar met die wat jy by almal gebly het en jy het genoeg geld in die bank. Dit is nie dat jy nie geld het of kortkom nie.” Dan sal jy nou byvoorbeeld sien dan loop sy nou na ‘n rak toe dan is daar pakkies sop of iets dan sê sy sy gaan die vat. Die oomblik as sy sien ek kyk nie vir haar nie dan sit sy dit terug in die rak. So op die einde van die dag as jy voor by die till kom dan het sy net so paar goedjies, maar jy het about drie ure daar rondgekoop. Dan het sy net so paar goedjies gekoop...want alles moet net om jou draai. Weet jy raak so, hoekom moet alles nou om jou draai?”* **Translation:** You uhm, I’ll tell you what I think, she realised that everyone is doing everything for her, because at that stage you felt so sorry for her that you didn’t want her to do anything, you’ll do it for her, you know? She couldn’t work with her money yet, so I would withdraw the money and buy what she needed. Then she realises that everyone feels sorry for me, and will do everything for me. I think then they take advantage of it. Listen, if I speak you should listen. And if you don’t then there is hell to play...For example you’ll tell her, “We’re in Checkers, buy what you think you need and what you feel like so that you don’t go hungry during the week. You saved up enough by staying with everybody. It is not that you need money.” Then you’ll see she walks toward a shelf with soup or something and say she’s going to take this. The minute she sees you’re not looking then she puts it back on the shelf. At the

end of the day if you're at the till, she only has a few items but you walked around for three hours. She only bought a few items...everything has to be on your terms. You know, you become like, why does everything have to be according to your way?

Participant G: *“Breinbesering is absoluut selfsugtig, ek meen, hy...hulle is selfsugtig, hy weet nie eintlik hy doen dit nie, maar dit is wat hy doen, hy’s baie selfgesentreer, so hy voel eintlik vere vir almal rondom hom. Al waaroor dit nou vir hom gaan is oor homself, as hy nou wil eet, wil hy nou eet; as hy nou wil bad, wil hy bad; as hy nou wil slaap, wil hy slaap. Hy het nie ‘n saak of daar mense is, of daar familie is of wat ookal nie – hy voel vir almal vere.”* **Translation:** Brain injury is absolutely selfish, I mean, he...they are selfish, and he doesn’t actually know he is doing it, but he does. He is self-centered, so he doesn’t care about the people around him. All that matters is himself, if he wants to eat, he wants to eat now; if he wants to bath, he wants to bath; if he wants to sleep, he wants to sleep. He doesn’t care if there are people or family or whatever, he doesn’t care about anybody.

Discussion of sub-theme 7.7

For the researcher, the sub-themes of social immaturity and selfishness go hand in hand. The behaviour described can be classified as both immature and selfish. Participants, who commented on selfishness, were all from the category wife/husband. This meant that they were not only taking care of their husband or wife who had a TBI, but also the household and children. One participant commented on how her husband demanded attention from her and was unable to wait his turn. In effect, it was like dealing with an extra child. This also had complications for their marital relationship. According to Kneipp (1991:169) “...the individual is exceedingly egocentric; the individual may persist in making demands on family members, without a word of thanks for their efforts”. Participants did not comment on ever receiving a word of thanks for their efforts.

3.6.2.8 Theme 8 and sub-themes: Future

Theme eight: Future	Sub-themes: ❖ Responsibility ❖ Expectations
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Participants were asked about their views and feelings about the future with their family member with a TBI. What transpired through the interviews were that when thinking about the future, participants were concerned about the responsibility. The other sub-theme identified was their expectations about the future.

• **Sub-theme 8.1: Responsibility**

Participant B: *“Kyk, ek weet net nie altyd...ek dink jou kinders. Ek weet net nie altyd hoe vat jou kinders hierdie ding nie, want soos ek sê daar is nie tyd om te gaan sit en vir Xxx (child) te vra hoe vind jy pappa se besering nou? Is jy oraait daarmee? Hoe het hy teenoor jou verander? Want hy het baie teenoor haar verander sou ek sê.”*

Translation: Look, I’m not always sure...I think your children. I don’t always know how your children are handling this, like I said there isn’t time to sit and ask Xxx (child), how are you experiencing daddy’s injury? Are you OK with it? How did he change towards you? Because he did change a lot towards her, I would say.

Participant C: *“Ek het ’n kind om aan te dink ek het ’n kind se toekoms om aan te dink. Ek moet.”* **Translation:** I have a child to think about and a child’s future to think about. I have to.

Participant E: *“Ek is net bang hy raak nou weer roekeloos...maar soos hy sê hy sê: “Ma ek kan nie die ongeluk onthou nie ek kan nie dit onthou nie, en ek weet nie als wat Ma-hulle my vertel ek deurgemaak het in die hospitaal nie, wat Ma saam met my deurgemaak het nie, ek kan dit nie onthou nie, maar dit klink vir my dis die waarheid”, want ek het vir hom die foto’s gewys wat ons geneem het en die karongeluk vir hom gewys wat so sy naam staan daar onder so hy kan sien dis als die waarheid so en hy dis asof hy helder dink daaroor. Dis asof hy twee keer sal dink voor hy op ’n motorfiets sal klim saam met sy vriende sal ry of sulke dinge. Hy sal...”* **Translation:** I am scared that he will become reckless again, but as he says, he says I cannot remember the accident, I can’t remember it, I don’t know everything you tell me that I went through in hospital, what you went through. I can’t remember but it sounds like the truth, I showed him the photos that we took and showed the accident to him, his name stands underneath it so he can see it is the truth and it is as if he thinks clearly about it. It is as if he will think twice before climbing on to a motorcycle and drive with his friends. He will...”

Participant F: *“Ons is net skrikkerig, ons wil nie graag hê hy moet in Pretoria of ’n ander plek, ons wil hom hier onder ons vlerk hê. Kan jy verstaan? Ek weet nie of dit verkeerd is nie, want hy is ookal ’n man van in die 40. Op hierdie stadium is ek net te bang om hierdie kuikentjie onder die hoender hen uit te trek.”* **Translation:** We are weary, we don’t want him to stay in Pretoria or another place, we want him here with us. Can you understand that? I don’t know if it is wrong, because he is a man in his forties. At this stage, I am worried to let this chick out from under mother hen.

Participant G: *“Dan dink ek, ek sien die skade wat dit doen aan die kinders, ek sien hom skreeu op die kinders, ek sien hoe begin die kinders swak doen by die skool. Jy weet, ek...ek kan die invloed sien en dan...dít breek jou heeltemal af, want jy voel half verantwoordelik vir jou kinders en jy probeer hierdie goedjies regmaak nou. Weet, naderhand het my kinders gegaan vir terapie en toe, en ek het regtig besef – op ’n stadium – as dit die rede is hoekom ek moet gaan, dan sal dit ter wille van hulle wees. Om hulle nou al die, hierdie skade nou aan te doen.”* **Translation:** Then I think, I see the damage it does to the children, I see him screaming at them, and I see how they do poorly at school. You know, I...I can see the influence and then...that breaks you down completely because you feel responsible for your children and try to fix these things. You know, eventually my children went for therapy and then I really realised, at one stage, if this is the reason for me to go, then it will be for them. To prevent further damage to them.

Discussion of sub-theme 8.1

Participants were asked how they felt about the future with their family member with a traumatic brain injury. The responses were mostly positive. All the participants in the category husband/wife stated that they were concerned about their children and the effect of having a mother or father with a head injury will have on them. One participant said that she has to be positive because of her child. It therefore seems that participants with young children were concerned about the effect their circumstances would have on them. One parent participant stated that she was concerned that her son would become reckless. Even though participants seemed to be positive, some responses related to the big responsibility that lies ahead. This responsibility is at times daunting, especially if there are others to be considered, such as children. Masaux & Richer (1998:440) states that family members experience considerable changes in their quality of life following a TBI of a family member. Even though participants didn't mention this explicitly, when all of the quotes above are taken into consideration, there has most definitely been a change in their overall quality of life.

- **Sub-theme 8.2: Expectations**

Participant B: *“Dit gaan aanpassing vat. Ek sien nie hoe ek êrens op ‘n hopie kan gaan sit en sê jammer, jy het ‘n hoofbesering, ek stel nie meer belang nie. Met hierdie tyd het ek agtergekom hoe lief ek hom het, dit kan ek eerlik sê. Ek kan my toekoms saam met hom so sien, ek kan...Wel as ek dink aan emosies en ek dink aan hom en alles...uhm as dit so moet bly, dan moet dit so bly.”* **Translation:** It will take adjustment. I can't see how I can sit and say sorry, you have a head injury, I'm not interested anymore. By this time, I realised how much I love him, that I can say honestly. I can see my future with him like this, I can. Well, if I think of emotions and I think of him and everything...uhm, if it has to stay this way then it has to.

Participant C: *“Ek voel positief weet jy, want hy probeer. Soms probeer hy, soms probeer hy nie.”* **Translation:** I feel positive you know, because he is trying. Sometimes he tries and other times he doesn't.

Participant F: *“Man, ek voel op hierdie stadium tot hy miskien ‘n ander pos gekry het, is ek baie positief.”* **Translation:** Man, at this stage I feel until he can find another post, I am very positive.

Participant G: *“Weet jy wat, ek kan my...my pad saam met hom sien. Maar soos ek sê; sy medikasie-goeters is toe uitgesorteer en...en nou...weet, nou kan ek my pad oop sien.”* **Translation:** You know what; I can, I can see the road ahead with him. Like I said, his medication was sorted out and, and now...now I can see the way forward.

Discussion of sub-theme 8.2

Marcelissen (in Williams, 1991:92) described stress that can be exemplified by eight situations that generally contribute to stress experienced by families post head injury. Each stressor increases the frequency and intensity of reactions to loss. The one stressor that is applicable here, is uncertainty of the future. Rapid progress early on in the process may create expectations for prolonged steady progress. Participants are not able to fully plan for the future and the future is filled with many uncertainties. When talking about future expectations one participant said, if it has to stay this way, it has to. This almost gives the impression that she is stuck in this situation and is powerless to change anything. When talking about the future, the researcher also asked how participants would feel if there was no further progress. One participant stated that she feels hopeful because she can see that her husband is trying. Another said she would feel hopeful if her son found alternative employment. It seems as if participants generally felt hopeful, as long as certain conditions were met: if the person with TBI could find alternative employment, as long as the person was trying, as long as medication issues were sorted out. Even though participants now feel positive, it may create difficulty when these situations change or conditions are not met.

3.7 Summary

The following themes and sub themes emerged from this research:

Theme one investigated the family's understanding of TBI. The sub-themes identified were knowledge of TBI, bodily harm versus cognitive impairment and personal meaning of TBI. For some family members, the meaning of TBI is more theoretical and for other more personal. When the person with a TBI emerges from being in a coma, family members are relieved and the realisation of the effects of the TBI comes as a shock to them. Having a family member who had a TBI is difficult and confusing.

Theme two investigated the period of hospitalisation. The experience of family members include the effects of the trauma, the uncertainty of what the future holds, balancing hope with realistic expectations, the feeling that what they are experiencing is unreal, being afraid and feeling powerless to do anything.

Theme three looked specifically at the emotional journey of family members of a person with a TBI. This includes feeling sorry for the person with TBI, finding the whole process emotionally draining but still feeling the pressure to keep going on, feeling alone in dealing with TBI, profound effects on the marital relationship when one party has had a TBI, feeling socially isolated due to the person with TBI not being able to return to previous level of social functioning, adjusting to role changes that TBI brought about and neglecting themselves in caring for the person with TBI.

Theme four addressed the period of rehabilitation. It specifically looked at the experience of rehabilitation, what family members found the most difficult about rehabilitation, how they felt about the discharge from rehabilitation and if there were needs that were not addressed by the rehabilitation team.

Theme five focussed on the period post discharge. What was evident about this was that it is a very stressful, demanding and busy time adjusting to TBI. Family members have a constant responsibility to care of the person with TBI and assist them with everyday activities. Family members often feel guilty, especially if they become impatient. The person with TBI's mood often determines the mood of family members and the atmosphere in the home. TBI has many concomitant financial implications due to loss of income.

Theme six investigated support systems available to family members of people with traumatic brain injuries. Support came from family, friends and the church. Very few family members went for professional support. Family members indicated that support from the employer of the person with TBI was also important to them.

In theme seven, the effects of TBI emerged. The effects that were mentioned the most were memory impairments, laziness, impatience, lack of insight, being a changed person, aggression, anger, rudeness, social immaturity and selfishness.

The last theme, theme eight focussed on the future. Family members indicated that they had a certain responsibility for the future, especially in cases where young children were involved. Most family members felt positive about the future with the person with TBI, but there were some exceptions.

The following chapter will provide a summary, conclusions and recommendations regarding this research.

CHAPTER FOUR

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

In this chapter the summary of the research will be discussed. The focus will be on how the aim and objectives of the study were met, as well as if the research question was answered. Conclusions to this study will be drawn. These will be followed by recommendations for practice and future research.

4.2 Summary

The objectives, goal and research question will subsequently be addressed and how they were met.

4.2.1 Objectives of the study

The objectives of this study were as follows. To:

- conceptualise traumatic brain injuries (TBI), mechanisms of injury, signs and symptoms, effects of TBI, assessment tools and outcome measures, cognitive rehabilitation and management of long term complications;
- explore adult family members' experiences of their traumatic brain-injured family member's post-acute rehabilitation; and
- make recommendations for acute rehabilitation centres and for social workers in intervening with traumatic brain-injured patients' family members post-acute rehabilitation.

Each objective will be discussed individually and how it was achieved through the research study.

Objective One: To conceptualise traumatic brain injuries (TBI), mechanisms of injury, signs and symptoms, effects of TBI, assessment tools and outcome measures, cognitive rehabilitation and management of long term complications

This objective was achieved through the conducting of a literature study of traumatic brain injuries and aspects that affected family members of people with TBI's. These factors were presented in Chapter Two of the research report. The literature chapter explored the following factors: traumatic brain injuries, assessment scales and outcome measures, rehabilitation and family reaction to TBI.

Objective Two: To explore adult family members' experiences of their traumatic brain-injured family member's post-acute rehabilitation

This objective was achieved by means of the empirical research. The data collected from one-on-one semi-structured interviews revealed that trauma, uncertainty, powerlessness, personal resources, the effects of the TBI, financial implications, the experience of the period post discharge and the emotional changes in the person with TBI, contributed to each one's personal experience. Participants were given the opportunity to share their own experiences, feelings and perceptions.

Objective Three: To make recommendations for acute rehabilitation centres and for social workers in intervening with traumatic brain-injured patients' family members' post-acute rehabilitation

This objective was achieved by means of the empirical research. The data collected revealed themes on the periods of hospitalisation, rehabilitation and post discharge, the effects of the changed person, other behavioural and cognitive limitations and financial and personal implications which provided an insight into the experience of family members of a person with a TBI. In this chapter recommendations are made for social workers and acute rehabilitation centres in dealing with people with TBI and their families.

4.2.2 Goal of study

The goal of the study: **To explore the experiences of adult family members of their traumatic brain-injured family member's post-acute rehabilitation**, was thus met by achieving all the objectives set out for the study. In summary, the goal was thus achieved as follows:

The literature chapter explored the following factors: traumatic brain injuries, assessment scales and outcome measures, rehabilitation and family reaction to TBI. Under traumatic brain injuries, mechanisms of injury, physical effects, cognitive effects and social, emotional and behavioural limitations were elaborated on. Under Assessment scales and outcome measures the Glasgow coma scale (GCS), the Rancho Los Amigos Scale of Cognitive Functioning, international classification of functioning, disability and health and functional independence and functional assessment measures were studied. Rehabilitation was explored with regards to working of a rehabilitation unit and the role of the social worker. Under family reaction to TBI, caregiver and family needs were discussed.

The empirical research yielded the following themes: understanding of TBI, period of hospitalisation, family members' emotional experience of TBI, period of rehabilitation, period post discharge, support systems, effects of TBI and future expectations were identified. Each of these themes had sub-themes which assisted to provide more detailed information on the experience of adult family members of their family member's traumatic brain injury. Understanding of TBI had the sub-themes of knowledge of TBI, bodily harm versus cognitive impairments and personal meaning that family members attached to their experience of TBI. Investigating the period of hospitalisation revealed sub-themes of trauma, uncertainty, hope, feeling unreal, fear and powerlessness, all related to family members' experience. Probing family members' emotional experience of TBI disclosed that they felt sorry for the person with TBI, found the process emotionally draining, felt pressure to continue while feeling alone, experienced effects on the marital relationship, experienced social isolation and role changes and neglected themselves. Studying the period of rehabilitation showed family members' experience and what they found the most difficult, how they felt about discharge from hospital and if there were any needs that the rehabilitation team did not address. The period post

discharge was described as a very stressful, demanding and busy time for family members with constant responsibility, guilt feelings, the need for patience, financial implications and revealed how the family member with TBI impacted on their own emotional state. The theme of support systems identified family, friends, religion, professional emotional assistance and understanding from the person with TBI's employer as sources of support. The effects of TBI that most impacted on family members were memory, laziness, impatience, lack of insight, the changed person, aggression/anger/rudeness, social immaturity, selfishness and manipulation. When talking about the future, family members admitted that they were concerned about the responsibility and talked about their expectations.

4.2.3 Research question

The research question was:

What were the experiences of adult family members of the post-acute rehabilitation of their family member with a traumatic brain injury (TBI)?

The data collected from the one-on-one interviews, once transcribed, revealed various themes and sub-themes, relating to the experience of family members of a person with a TBI. As the research was qualitative in nature, descriptive data was obtained. These descriptive experiences of the family members were presented in the previous chapters on research findings. The following themes which were found, reflect the experience of adult family members of their family member with a traumatic brain injury (TBI) post rehabilitation:

- Theme One – Understanding of TBI
- Theme Two – Period of hospitalisation
- Theme Three – Family members' emotional experience of TBI
- Theme Four – Period of rehabilitation
- Theme Five – Period post discharge
- Theme Six – Support systems
- Theme Seven – Effects of TBI
- Theme Eight – Future

These themes were discussed in-depth, together with their sub-themes in the previous chapter.

Table 5: Table of themes and sub-themes

THEME	SUB-THEME
Understanding of TBI	<ul style="list-style-type: none"> ❖ Knowledge of TBI ❖ Bodily harm vs. cognitive impairments ❖ Personal meaning of TBI
Period of hospitalisation	<ul style="list-style-type: none"> ❖ Trauma ❖ Uncertainty ❖ Hope ❖ Feeling unreal ❖ Fear ❖ Powerlessness
Family members' emotional experience of TBI	<ul style="list-style-type: none"> ❖ Feeling sorry for the person with TBI ❖ Emotionally draining ❖ Pressure to keep going ❖ Feeling alone ❖ Marital relationship ❖ Social isolation ❖ Role changes ❖ Self neglect
Period of rehabilitation	<ul style="list-style-type: none"> ❖ Rehabilitation experience ❖ Most difficult about rehabilitation ❖ Feelings about discharge ❖ Needs not addressed by team
Period post discharge	<ul style="list-style-type: none"> ❖ Very stressful, demanding, busy time ❖ Constant responsibility ❖ Feeling guilty ❖ Patience ❖ Routine ❖ TBI person determines emotional state ❖ Financial implications
Support systems	<ul style="list-style-type: none"> ❖ Family ❖ Friends ❖ Religion ❖ Professional emotional support ❖ Employer support
Effects of TBI	<ul style="list-style-type: none"> ❖ Memory ❖ Laziness ❖ Impatience ❖ Lack of insight ❖ Changed person ❖ Aggression/anger/rudeness ❖ Social immaturity ❖ Selfishness ❖ Manipulation
Future	<ul style="list-style-type: none"> ❖ Responsibility ❖ Expectations

4.3 Conclusions

It is the opinion of the researcher that the findings of this study cannot be generalised, but could be transferable to a similar rehabilitation setting with a similar population. Analysis was done according to the data analysis process used for the qualitative approach.

The qualitative approach, using collective case studies and one-on-one semi-structured interviews, proved to be the appropriate research design, as the information gathered was in the form of words and descriptions to give meaning to the experience of family members of people with a traumatic brain injury (TBI). The researcher was able to obtain first-hand information through the use of the semi-structured interview schedule (Appendix 1), as it allowed some flexibility to explore certain topics further. It can therefore be concluded that the semi-structured interview schedule as a method of data collection used in interviewing, worked effectively in answering the research question. The researcher can therefore recommend these methods to future researchers who are aiming to explore experiences of family members of people with TBI. The collective case study design was appropriate as the researcher was able to expand her understanding of the experience of family members of TBI patients, by exploring the experiences of different families (case studies) and these findings from the collective cases were presented in the common themes and sub-themes found.

4.3.1 Theme One: Understanding of TBI

It is important for family members to understand their family member with a TBI's diagnosis. The researcher argues that having more knowledge can contribute to understanding the treatment process and what to expect. In this study not all participants showed a good and clear understanding of TBI and it is the researcher's opinion that this knowledge contributed towards family members showing poor or good insight into the person with TBI's condition and limitations which in the end affected their experience. Family members with good insight will have a better understanding of the limitations which will contribute towards a more positive experience. Participants also came to realise that there is a difference between dealing with physical

impairments and dealing with long term cognitive and behavioural limitations. The findings clearly showed that family members were initially so relieved that the person with the TBI survived, that they did not realise what the effect of the TBI was. The researcher argues that this realisation brings along with it a range of emotions which negatively affects the relief that they were experiencing. It is also the opinion of the researcher that if there is a good and clear understanding of TBI, these emotions can be minimised as it would create more realistic expectations.

Sub-theme: Knowledge of TBI

From the research findings it was noted that some of the participants attached a very personal meaning to TBI and others had a more theoretical explanation of what a TBI is. TBI is a serious injury and participants commented on that, whether referring to the serious physical injuries or to the more cognitive and behavioural effects of TBI. One participant commented on how it was a whole new world for her. It is the researcher's opinion that TBI brings about great change in the lives of family members and that having good knowledge of TBI will help them to understand this new world they have become a part of.

Sub-theme: Bodily harm vs. cognitive impairments

Initially family members of patients with a TBI were concerned about the visible injuries, i.e. physical injuries. Only when the person started to emerge from the coma and started communicating, could family members see what other effects there were. And these cognitive and behavioural effects are often longer lasting.

4.3.2 Theme Two: Period of hospitalisation

The period of hospitalisation is mainly characterised by stress and uncertainty. Family members may face the question whether their loved one with a TBI might live or die. Family members are also severely traumatised due to their experience in ICU, seeing a family member with severe injuries and disabilities. After he or she has been stabilised and has emerged from the coma, a new form of stress is experienced: that of to what extent the person would recover and what residual effects of the TBI would remain. During this time, family members face a great deal of trauma in the process of dealing with TBI. It is argued that they have to balance fear and hope in order to mobilise

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 the opinion of the researcher that the trauma is further complicated by now knowing what to expect and the sadness and fear leads to anxiety. It is further argued that this anxiety has a profound effect on their 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 to have an expectation that things will become better than what they are, but in dealing with TBI often there is no hope because medical personnel do not want to create unrealistic expectations.

Sub-theme: Trauma

Family members deal with the traumatic experience of facing the possibility of death of their family member with a TBI and having to witness the severe injuries. It is also the uncertainty in the first days that contribute to the trauma. From the research findings it was noted that family members felt traumatised by the way their family member with a TBI looked, i.e. swelling, intubation, behavioural and cognitive limitations. Family members of people with traumatic brain injuries suffer from trauma due to what they witnessed in ICU and the effect extends well into the period after discharge from hospital.

Sub-themes: Uncertainty, fear, anxiety and powerlessness

The three sub-themes focussed on similar aspects of coping during the ICU period and the responses were similar. Family members stated that they did not know what to expect; would the person with the TBI recover and to what extent? The term *traumatic brain injury* was experienced as vague because after hearing it family members still did not know what to expect and what the degree of the injury was. Family members found it difficult to plan and to carry on without knowing what was going to happen. They had no control over the situation and were left feeling sad and could only hope and pray that everything would work out for the best. This led to anxiety and fear about the uncertainty of the future and it carried on for some time as many reported that the person was in a coma for months. The uncertainty and anxiety became a way of life for them. Participants reported that they had a need to not be a passive member of the process, but wanted to do something. The inability to have any control over what was

happening in the ICU lead to feelings of powerlessness and the realisation that they were unable to do anything to assist was very difficult.

Sub-theme: Hope

Family members experienced a fluctuation in emotions ranging from despair to having hope for the future. They also focussed on the person with TBI and his or her progress in order to be hopeful for the future. When they witnessed progress, even if it was ever so little, it helped them to feel hopeful for the future. Family members of a person with TBI who is in ICU has a need to hope, something to keep them going in order to carry on. Progress helps family members to draw hope even though doctors tell them not to hope and it seems that this hope helps to mobilise them during the uncertain critical stage.

Sub-theme: Feeling unreal

This sub-theme links in well with the sub-theme one, trauma. The feeling that what has just happened was just a bad dream could be because of the trauma or just a normal reaction to the losses perceived. The researcher is of the opinion that this feeling that things are not real, is a combination of the trauma and a reaction to the losses experienced. It is also a coping mechanism to deal with this critical stage. As time passed, family members got used to the situation as it was and started to digest the information, assisting them to internalise what was going on.

4.3.3 Theme Three: Family members' emotional experience of TBI

The overall experience of family members of a traumatic brain injury is highly emotional in nature. TBI is a family affair; it does not only affect the individual but has far ranging consequences for the whole family. Family members have to cope in an uncertain and ever-changing world. Family members experience mixed emotions ranging from having great sympathy for the person with TBI to feeling angry and struggling to cope with the changes in their lives. It is argued that all that comes with having a family member with a TBI is an emotionally draining process, mostly due to the long recovery process and the draining of all emotional resources. It is the opinion of the researcher that in many cases, by the time the family takes the person with TBI home, all of their emotional resources have been depleted and it is exactly now that they will need them the most.

Furthermore, most family members don't recognise this and feel pressurised to carry on as there is no-one else to take over the responsibility. There are complicated implications for the marital relationship where one of the parties is the person with the TBI. The researcher found that the scope of this study did not allow for an in-depth exploration of the marital relationship but that it should be addressed in future research. The last argument for this theme is the issue of self neglect. Family members did not seem to have the skills to cope with the demands of caring for their family members and look after themselves as well. This can possibly have far-reaching repercussions because if the family member who is the primary caregiver falls apart, in many instances there are no other plan in place to care for the person with TBI who is unable to care for him or herself.

Sub-theme: Feeling sorry for the person with TBI

Experiencing traumatic brain injuries is very confusing emotionally for family members, with emotions ranging from feeling sorry for the person with TBI and feeling angry at them for the changes in their lives. Feeling sorry for the person with TBI also leads to family members wanting to do everything for that person, which is conflicting to what is taught in rehabilitation. There retraining is done in order for the person to do as much as possible for himself or herself.

Sub-theme: Emotionally draining

Dealing with a family member with a TBI is emotionally draining. The uncertainty of wondering how to cope and what uncertainty about the injured person, are all emotionally draining. While dealing with TBI, family members don't get respite from the normal day-to-day responsibilities. They still have to continue with other responsibilities and caring for other family members. While the person is still in hospital, family members are tired out by driving to and from hospital. The period of hospitalisation is long and family members indicated that they found it very tiring to travel to and fro, day after day. Some family members found it difficult to sleep and stated that they were so tired, but kept going because they felt they didn't really have a choice.

Sub-theme: Pressure to keep going

Family members of people with traumatic brain injuries have very little time to contemplate and they feel pressurised to persevere with what they need to do. At times they feel this pressure to keep going for the sake of others, for example their children. It is a very difficult time for them but they cannot slow down because they much to do and have to attend to all of their responsibilities. The whole process of dealing with TBI is exhausting, but the following day they have to get up and start all over again. Family members feel the need to keep going because there isn't someone who can help them, this is the burden they have to carry.

Sub-theme: Feeling alone

After the person with a TBI is discharged from hospital, family members feel very alone. They have this overwhelming feeling that they are now solely responsible for this person. They have to face tasks such as child-rearing, on their own and at times it is very difficult. Especially when things get tough or there are problems, the person with TBI is not able to take on joint responsibility. It is all left to family members. Family members sometimes have a need for assistance for certain tasks, but in many instances there is no support available.

Sub-theme: Marital relationship

This sub-theme links in well with the previous one of feeling alone. When one person in the marital relationship suffers a traumatic brain injury, it changes the nature of the relationship. The spouse of the person with a TBI is now alone and in many instances the closeness experienced before has completely changed. They are unable to share their deepest emotions due to a variety of factors such as poor concentration and emotional immaturity. Spouses have to deal with their emotions in solitude. They can no longer expect emotional support from their husband or wife with a TBI. In effect, couples have to learn how to get to know each other right from the start. Due to all the changes and the adjustment needed thereafter, some couples experience a lot of friction. Due to effects of the TBI such as tiredness, spouses experience the loss of companionship in the relationship, as their partner goes to bed very early. This again leads to feeling alone in the marital relationship.

Sub-theme: Social isolation

Family members of people with TBI are socially isolated. This is due to the person with TBI struggling to manage himself or herself in social situations. They still tire easily and some find it difficult to express themselves. Others find that the changes are just too difficult for friends and other people to handle. Many families with a person with TBI avoid social gatherings because it is just too difficult. This leads to family members having little social contact with others. Family and friends are an important source of support to family members of people with TBI and avoiding social gatherings creates social isolation, which in turn affects the support network available to family members.

Sub-theme: Role changes

The research results indicated that women especially found it difficult when they had to take financial responsibility for the family. Not only the role-change, but the responsibility that came along with this change, they found very difficult. Also, their husbands were more like children than their husbands. This links in well with the sub-theme above on the marital relationship. Role changes were some of the key issues that were identified as challenges to cope with in their marital relationship.

Sub-theme: Self neglect

Again, this theme linked in well with the sub-theme of the marital relationship. As part of the marital relationship, the spouse of the person with TBI neglected him- or herself in order to cope with the situation and provide everything that the family member with a TBI needed. This is especially relevant for families where there are young children. The spouse without the head injury gives priority to the needs of their spouse and young children and neglects her- or himself. Spouses in this situation are so consumed with caring for the person with TBI and caring for their young children that there is so little time and energy left to focus on their own needs.

4.3.4 Theme Four: Period of rehabilitation

The period of rehabilitation is a difficult time for family members of people with traumatic brain injuries. It is during this time that the reality and effect of the TBI become more visible, as patients are taken out of bed and partake in daily therapy sessions. This is also the last phase of hospitalisation and families have to prepare themselves to take the person home. This study showed that social support was

instrumental for patients in achieving therapeutic goals and during this time it was also important for family members. It is argued that even though families mostly had a good experience of the period of rehabilitation, they still found the emotional demands difficult to cope with. It is the opinion of the researcher that family members felt a sense of loyalty towards the rehabilitation unit and staff and really formed good relationships with them and was therefore unaware of certain limitations to the service they experienced.

Sub-theme: Rehabilitation experience

Family members that participated in this study all had a positive experience of rehabilitation. Responses yielded, ranged from a good experience to a wonderful experience. Family members could see that there was progress and that is was very different from the ICU. Family members felt that the staff of the rehabilitation unit supported them and it felt like a second home. It is important for family members to form good relationships with the staff of the unit in order for them to put their trust in the procedures.

Sub-theme: Most difficult about rehabilitation

Rehabilitation is the period when family members realise that they have to take the person with the TBI home. They are sometimes full of hope, but are often reminded by the doctor not to be too hopeful. Rehabilitation is difficult for family members due to the long period of hospitalisation and because progress is not always visible to them. During this time it is also difficult for family members to visibly see the effect of the TBI, patients are taken out of bed and put into wheelchairs and all effects of the TBI is shown and explained to family members. During this time, family members need support to understand and absorb all the changes.

Sub-theme: Feelings about discharge

Once a discharge date has been set, family members experience high levels of stress due to various reasons. They are scared to take the person with a TBI home. They are concerned that they will not know what to do with him or her and that they will not be able to care for them as well as they were taken care of in the hospital. Some families are scared that the person might fall and injure themselves again. The parents of patients with TBI indicated that they wanted to protect their children without being over-protective. Family members were also concerned about the cognitive and behavioural

consequences of the TBI and how they would be able to endure the changes. Discharge from rehabilitation is a scary time for family members.

Sub-theme: Needs not addressed by team

Family members that participated in this study felt that the rehabilitation addressed more than what they expected it to. They felt they were adequately prepared for what lay ahead.

4.3.5 Theme Five: Period post-discharge

The period after discharge from rehabilitation is a very stressful time. Family members have to get to know one another again, and become accustomed to each other again. Not only do they have to become used to each other again as they were before, but often the person with TBI is experienced as a completely new person, which causes a lot of stress and anxiety. It is usually also the first time that the family is responsible for the person with TBI for longer than a weekend. It is argued that coping with a family member with TBI for a weekend and knowing that that person is returning to a rehabilitation unit is not nearly as scary and demanding as caring for a person with TBI on a full time basis. It is also during this time that family members are forced to come to terms with the TBI and the changes it brought to their lives. Other stressors further complicate family members' coping and adjustment such as not having the time to allow themselves to internalise what is happening. The researcher would like to emphasise that during this period the responsibility is constant without any escape from it. There is thus no time or scope for family members to focus on themselves and to constantly empower themselves to cope with the daily challenges of caring for a person with TBI. It is further argued that family members place a very high burden on themselves of being the perfect caregiver and often are faced with a feeling of guilt when they, for example, have lost their patience. It is the opinion of the researcher that if family members are coping well and have adequate skills and time for relaxation, they would suffer less from feelings of guilt and not having enough patience. They will then also be better equipped to handle conflict situations. The researcher would like to add that the stress that comes with severe financial constraints and not knowing how to resolve the matter or where to get help, further affects their ability to cope with the daily demands that caring for a person with a TBI brings.

Sub-theme: Very stressful, demanding, busy time

This time after discharge from rehabilitation is very difficult for family members. They have to continue with work during the day and in the evenings and during the night, take care of the person with TBI. It is a time that is very exhausting due to the cognitive deficits of the person, concerns that he or she will hurt themselves and due to all the caregiving and household activities that have to be completed. Alarm clocks have to be set for medication and that, together with the activities mentioned above, leave very little time for rest and relaxation. Family members feel that there isn't even time for breaking down emotionally and crying. Some people with TBI are also still disorientated and restless at the time of discharge, which leads to caregiving being a 24-hour responsibility, often with very little help.

Sub-theme: Constant responsibility

Taking care of a person with TBI is a full time occupation. Family members are always responsible. They find it difficult to sleep because they are concerned. Some find it difficult to cope due to the many responsibilities and tasks. Family members cannot leave the person with TBI alone; they have become very dependent on them and need them to perform even basic tasks such as bathing and eating. Family members are often burdened by feeling responsible for everything, not only for the person with TBI but young children as well. There is no escape from the daily responsibilities and no opportunity to focus on themselves.

Sub-theme: Feeling guilty

Family members struggle with feelings of guilt after TBI for a variety of reasons. Mainly they feel guilty when they become fed-up and lose their temper. When their frustration negatively influences their relationship with their children, they feel very guilty. Feeling guilty is something most family members of a person with TBI experience on a regular basis.

Sub-theme: Patience

Dealing with TBI, teaches family members patience. Family members who did not necessarily think of themselves as patient people, learned to be patient with their family member who has a TBI. Some family members felt that there was simply not enough

time to become impatient. Patience is also linked to progress. When family members felt impatient but saw progress, it seemed to ease these feelings of impatience. Family members also reached a point when they became exasperated and then lost their temper.

Sub-theme: TBI person determines emotional state

Family members of people with traumatic brain injuries found that their own emotional well-being is largely affected by the mood and behaviour of the person with TBI. Some family members tended to ignore their own feelings and largely focus on the needs of the person with TBI and on that of their children. Cognitive and behavioural effects of TBI often influence the atmosphere in the home and the well-being of family members were largely affected by these.

Sub-theme: Financial implications

After TBI, most families are faced with great financial constraints. They have already depleted all financial resources and together with loss of income of the person with TBI, families face great difficulty. Many families were also left with many medical bills that had not been paid by their medical aid. At times, lack of insight of the person with TBI led to unwillingness to contribute financially. Some family members felt that their financial difficulties were the most difficult for them to handle.

4.3.6 Theme Six: Support systems

The researcher found that family members received support from family, friends, their religion and church, professional support and the person with TBI's employer. The responses were very individual in nature, with some family members receiving good support from family and friends and others not. What did seem to transpire is that support systems changed over time. The group of friends that were very supportive during the critical stages did not seem to be so supportive later. They found it difficult to cope with the changed person and wanted to remember him or her the way they were. Other families felt that family members were there to support them, but not in the way they really needed. There seemed to be a discrepancy between what family members expected of the rest of the family and what they received. All in all, it is the

researcher's opinion that family and friends remain the most important source of support for a family who has been affected by TBI.

The results indicated that many family members found a great source of support from their religion. This relationship was not affected by human error as in the case of friends and family members who disappointed them. Some family members indicated that they had a need for more professional support. They further indicated that while they did not necessarily have the need for such support by the time of discharge, they did have that need as time went by. It is the opinion of the researcher that by that time, family members suffered from severe burn-out and did not have the emotional resources to even seek help or assistance. They also felt that they had to cope on their own and therefore did not have the courage to admit that they were not coping.

Family members of people with TBI were affected by severe financial constraints as was seen in the previous theme. The researcher found that this was one of the most significant difficulties that family members had to cope with and one that they did not know how to overcome. To overcome these difficulties, employer support was very important. The results of the study showed that only one participant continued to receive her salary throughout her recovery period, until she was able to return to work. Others had little or no support, which is difficult for family members who have to cope with many other stressors as well. It is argued that family members require more support in dealing with the financial constraints that loss of income and increased financial burdens as a result of TBI brings.

4.3.7 Theme Seven: Effects of TBI

Dealing with the effects of TBI can be very difficult for family members. The cognitive and behavioural effects are often more challenging than the physical effects. The recovery period is long and often the residual effects are still present years after the injury. It is argued that family members are not adequately prepared for what possible effects to expect when the person with a TBI emerges from a coma. Family members are so relieved that the person is surviving the ordeal that they are shocked when they experience all the cognitive and behavioural limitations. Most families understand that the majority of physical effects can still heal but that the recovery of cognitive and

behavioural effects of TBI remains uncertain. The theme of the effects of TBI is a very significant theme because these are the issues that family members have to cope with on a daily basis and they largely affect their experience of TBI in general.

Sub-theme: Memory

Dealing with a family who has a mild to severe memory impairment is very frustrating. Family members are unable to discuss issues because by the following day, the person is unable to remember what had been discussed. The results indicated that family members found it difficult and were shocked when the person with TBI was unable to remember certain family members or significant others. Family members also found it very frustrating if objects were lost or misplaced on a daily basis. It also meant that family members could not give the person with TBI certain instructions as the memory impairment led to them being unable to complete them. Again this led to family members bearing the full responsibility.

Sub-theme: Laziness

Family members of a person with a TBI experienced that the person had become lazy. Family members included in this study did not receive any assistance with domestic tasks from the person with TBI. Some experienced that the person with TBI was more untidy than they were before the injury. Family members found it difficult that they had to instruct the person what to do, because if requested, they did not assist. The literature suggests that the apparent laziness is in actual fact problems with initiation that result from TBI. The researcher believes that the reasons for this behaviour were not important, family members still found the situation difficult and perceived the person as lazy.

Sub-theme: Lack of insight

When a person with TBI has poor insight into his or her condition or limitations, it requires a lot of patience and adjustment from the family. The results of the study showed that family members had difficulty particularly when there was no insight into the fact that they had outbreaks of anger. Family members were concerned that when the person with TBI returned to work, the poor insight of the person with TBI would not be received well as other people might not have adequate knowledge or patience to handle it correctly. Poor insight also led to people with TBI blaming family members for

certain rules or the long hospitalisation period. Another complication of poor insight was not adhering to a medication regimen, which was extremely difficult for family members to deal with.

Sub-theme: Changed person

The results of the study indicated that family members struggled with the fact that the person with TBI had changed completely in terms of personality. They experienced the person as a completely different person and not the person they knew. It was a difficult adjustment. Some family members found the new traits of the person with TBI, such as the aggression, very upsetting and difficult to deal with. Family members in effect had to mourn the loss of the person they knew and loved, and adjust to the new person who did not always treat them well. They had to find the courage to continue caring for the person with love and compassion, while they felt that they did not really know her or him and at times did not really like this person.

Sub-themes: Aggression, anger and rudeness

Family members described the aggression and anger as unbearable. They referred to the amount of screaming and swearing in their homes. Sometimes the unpleasantness was not due to aggression or anger but rudeness, such as the person with TBI being unwilling to talk to certain people. This was difficult for family members, especially those who were the primary caregivers deprive themselves to look after the person with a TBI. Some people with TBI's anger was so severe, that others including close family members were scared of them. Other family members commented on how anger and aggression sometimes led to embarrassing events. There were different effects of anger, aggression and rudeness on family members and family members lengthily described the effects on their lives. The researcher found that this was one the most significant effects that family members had to cope with over a prolonged period of time and with no respite.

Sub-theme: Social immaturity

Family members experienced the person with TBI as immature. This caused severe conflict, especially with young children or teenagers in the home. It was difficult for family members because in effect they had to deal with another child in the home as the person was unable to act like a parent or spouse. There was little consistency in

the way they acted; they never knew how they would react. This led to difficulty for family members because the issues could not be discussed in a mature way. Family members experienced despair and the researcher found that they did not know how to handle these situations. Social immaturity prevents family to resolve issues surrounding the person with TBI and leads to that person being unable to take any responsibility for his or her own actions. This creates a large amount of frustration for family members dealing with TBI.

Sub-theme: Selfishness

Another effect of TBI that family members found hard to deal with was selfishness. The person with TBI was perceived to be selfish when they insistent on having their needs met and were unable to wait their turn. It was especially frustrating for families where there were young children who did not understand how to compensate. Family members experienced that they were being manipulated and at times taken advantage of. It was difficult for them to stay motivated because they experienced that the person with TBI did not care about them.

4.3.8 Theme eight: Future

The results indicated sub-themes in this theme of future responsibility and future expectations. Family members with young children were especially concerned about the effect on them. Other family members were concerned about what would happen to the person with TBI in the long run. Family members generally felt positive, especially when they could see the person with TBI put in some effort and was trying hard. When talking about future expectations, most family members felt positive, but with some exceptions and on certain terms, such as medication to be sorted out and the person with TBI finding employment.

As can clearly be seen from the above arguments regarding the experience of family members of a person with TBI, the matter in general is very complex and unique to each family. Family members are faced with daily challenges – first with the trauma of the accident and then to cope with the residual damage of the injury. Family members are in dire need of support, which is not always readily available. Having a good understanding of what to expect of the process can help ease the confusion and assist

family members in understanding the process. Challenges that family members face can then be viewed in different angles, i.e. the themes of this study: understanding what has happened to their family member with a TBI and internalising the medical explanations into a more personal meaning – facing life and death during the period of hospitalisation, first in ICU and after that the uncertainty that rehabilitation brings. Through the whole process, families must face different emotions which are complicated by uncertainty, anxiety and fear. The period of rehabilitation includes intense training, education and support for people with TBI and their families in order to prepare them for the rest of their lives. This support is to a large extent removed once the person has been discharged from hospital and the family needs to mostly cope on their own. The period after discharge brings other challenges such as financial difficulties and adjusting to new family roles. The researcher found that not all families have unrestricted access to support, whether personal or professional in nature. There are a variety of effects of the TBI that have an impact on families in different ways. It was found that cognitive and behavioural effects have a greater impact on families than physical effects. In the end, most families feel that they can draw strength from their experience and face the challenges that the future might bring.

4.4 Recommendations

Subsequently the recommendations will be made per theme:

4.4.1 Recommendations – Theme One: Understanding of TBI

Education as part of hospitalisation remains very important. The researcher believes that education should be continuous and not a one time event. As was seen from the literature, families listen selectively and information needs to be repeated. The researcher further believes that families receive an overload of information, which makes it difficult to remember and for that reason facts needs to be repeated by all team members, but especially the social worker who deals with the family on a daily basis.

The researcher believes that support from a social worker is vital in the critical ICU stages, when the person with a TBI emerges from a coma in the ICU. Education at the

time of the patient's emerging from a coma is very important in order for families to understand what they are witnessing and to prepare them for what lies ahead, especially in terms of the cognitive and behavioural effects of the TBI. It is therefore recommended that there are more involvement and intervention from social workers in the critical ICU stages. This intervention should focus on education, preparation and emotional support.

4.4.2 Recommendations – Theme Two: Period of hospitalisation

Family members usually found the first visit to the ICU traumatising. The researcher believes that social work intervention in this critical stage can help minimise the effect; family members should be prepared for what they are about to see prior to their first visit to the ICU. It will benefit family members to have an opportunity after the visit to verbalise what they saw and how it affected them and the social worker can facilitate this process when possible.

In dealing with the uncertainty that this period brings, again the support of a social worker is recommended. This social worker should be knowledgeable about TBI and be able to assist family members with their uncertainty, fear and anxiety. Not all uncertainty can be overcome with the availability of a social worker, but the researcher believes that having a link to the medical team will be beneficial to family members. It is recommended that the family has at least one appointment with the treating specialist prior to discharge from hospital.

When dealing with a family member who sustained a TBI, it is recommended that family members receive guidance and information on the stages of grieving, as dealing with a disabling condition is very similar to dealing with loss in the sense of death.

Family members dealing with TBI, experience feelings of powerlessness and it is recommended that family members be included in the treatment, with things they are able to do, such as caring for the person with TBI. The researcher strongly believes that family members will benefit from being actively involved and not only playing a passive role in the treatment process. Participation in decision making will also assist family members to overcome the feeling of powerlessness. Open, honest but sensitive

communication is suggested to keep family members updated on what is going to balance hope and realistic expectations.

4.4.3 Recommendations - Theme Three: Family members' emotional experience of TBI

Family members dealing with TBI, experience fluctuating emotions. It is recommended that family members be prepared for these feelings and also be taught ways to understand their feelings and how to act upon them. Due to the long recovery period of TBI, family members became emotionally worn out. It is recommended that this be discussed with family members. Family members should be assisted in developing a support structure from the start (prior to discharge from hospital), which they can rely on for support when they feel emotionally worn out. This support system can then be called on when family members feel under pressure, lonely and emotionally drained. The researcher believes that if healthy coping strategies and the importance of self-care are taught early on during in the process, it will greatly assist family members, especially after discharge when very few professionals are still involved on a daily basis.

Professional support is strongly recommended after discharge, especially for spouses of people with TBI. They are often very alone because the very person who is supposed to support them, is the person with the TBI. Group work with spouses of people with TBI is recommended. This will also enhance their social support network with people who understand what they are going through. The researcher also believes that this might aid family members who are struggling with social isolation, as outings can be planned according to the needs of the family members with TBI.

Discussion about different roles in the family and how TBI has changed these roles is recommended prior to discharge from hospital. The researcher believes that if family members and people with TBI are taught compensatory strategies on how to handle different roles, it might ease the burden on family members after discharge.

4.4.4 Recommendations – Theme Four: Period of rehabilitation

Rehabilitation differs greatly from the ICU setting which precedes it. It is strongly advised that family members be adequately prepared about what changes to expect from rehabilitation prior to transfer. Rehabilitation services should also focus on improving general well-being of patients and their families. Open, honest and regular communication is recommended. Family members of patients with a TBI in rehabilitation are often struggling, because this is the time that they come face-to-face with the effects of TBI. It is recommended that family members be treated with compassion and sensitivity about issues that are an everyday occurrence for staff members, but are frightening for family members. Family members struggle with fear and anxiety when discharge from rehabilitation is near. It is recommended that a step-by-step discussion of the uncertainties and fears of family members take place prior to discharge.

The development of a formal support organisation in the government sector is recommended. Currently there is no such support available in the Pretoria area. Such an organisation should be utilised to provide specialised support for families that are affected by TBI and assist with training of caregivers.

4.4.5 Recommendations – Theme Five: Period post discharge

Family members should be adequately prepared for the period post discharge. Healthy coping strategies should be taught on how to handle the demands of caring for a person with TBI. It is recommended that social workers working in the field of traumatic brain injury should discuss ways of how to balance the caregiving demands with demands of the household and employment, prior to discharge of the patient.

Currently there are no services available in Pretoria to assist family members with the demands of caring for a person with TBI, in order to give them some assistance in the form of respite care. The researcher believes that the development of such a service will greatly improve the quality of life of family members caring for a person with TBI, because it will bring about a good balance in the caregivers' lives.

Financial difficulty after TBI is one of the greatest obstacles that family members had to face. Often family members had no support in dealing with financial problems, as they only arose after the person had been discharged from hospital. The researcher believes that programmes to assist family members with dealing with their financial difficulties and to provide support, would greatly benefit families that were affected with TBI. This will give families the opportunity to turn somewhere for advice and guidance on how to handle the problems they experience with regards to finances.

4.4.6 Recommendations – Theme Six: Support systems

Support systems should be discussed with families prior to discharge from hospital. Not only support systems for the person with TBI, but for the family. The family is the biggest source of support for the person with TBI, but often support systems for families are not identified prior to discharge. The researcher believes that identifying adequate sources of support for the family will create an environment where family members have people to rely on on days when they are not coping too well. If family members could express their frustrations it would alleviate stress. Should there be no healthy relationship that family members can fall back on; a referral to a professional should be made. As discussed in the previous theme, financial difficulty was often a problem post discharge. To have the employer involved in the process might increase understanding and compassion, in order for a greater level of involvement. This will ensure that problems with employers not understanding the process be minimised. Support groups in the community for families with a TBI family member would be very beneficial.

4.4.7 Recommendations – Theme Seven: Effects of TBI

Cognitive and behavioural effects of TBI last longer than the physical effects and are often more difficult for family members to deal with. It is recommended that rehabilitation units run support groups that can focus among other things, on dealing with cognitive and behavioural effects of a TBI. This will include a professional component of dealing with these effects, but also create an opportunity for families of people with TBI to interact with each other and form supportive relationships. Referral for ongoing therapy such as social work intervention, occupational therapy and speech therapy, will also assist families in dealing with the effects of TBI. Unfortunately there

are very few social workers that have specialised knowledge and experience in working with TBI. Short course training programmes for health care social workers, focussing on TBI would be very beneficial. Furthermore, more emphasis should be put on rehabilitation and working with patients who have suffered TBI as a field of specialisation in postgraduate training in social work in health care programmes.

4.4.8 Recommendations – Theme Eight: Future

The researcher feels strongly that families with young children that have been affected by TBI should be referred for further social work intervention to address concerns of parents and provide guidance on how to deal with young children and a family member with TBI.

4.4.9 Recommendations for future research

Future research should be done on TBI family members from different racial groups and different age groups, and state versus private patients to see if their experiences are similar. A bigger national quantitative study would be beneficial. Another recommendation is a qualitative study exploring the support systems of families affected by TBI, especially focussing on the marital relationship, aiming to develop an extensive support structure and developing skills in order to equip people with a spouse with TBI in the South African context.

4.4.10 The way forward

Dealing with TBI is one of the most difficult obstacles that a family can face. Providing care and developing skills for family members who act as caregiver of their family members with a TBI can greatly enhance their quality of life and empower them to embrace their situation with enough courage and compassion to ensure that the vulnerable group of people with TBI is well taken care of. It is important for professional teams that work in the field of traumatic brain injuries to take into account the difficulties that families are facing. Social workers working in the field of TBI should educate other team members on family experience in order for them to take that into account. Where possible, families must be encouraged to participate in the rehabilitation programme in order to fully prepare themselves for the road ahead. It is the researcher's opinion that

no family should be discharged from rehabilitation without a referral for ongoing support or at least a contact person for families that have been affected by TBI.

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APPENDICES

**APPENDIX 1:
ETHICAL APPROVAL LETTER**

APPENDIX 2: INFORMED CONSENT LETTER

APPENDIX 3: INTERVIEW SCHEDULE

Appendix 3

Interview Schedule

Introduction

Thank you for agreeing to participate in my study. Before we begin I'd like to review the informed consent form in order for you to get a better idea of why this study is being conducted and about your rights as a participant in this study. If you have any questions at any time, please don't hesitate to ask.

Do you have any questions before we begin?

Interview Questions

1. Tell me about your understanding of traumatic brain injury.
2. Tell me about your family member that has a traumatic brain injury.
3. Discuss your experience of the rehabilitation process.
4. What was the most difficult experience in rehabilitation for you as a family member?
5. What needs, do you feel have not been met by the rehabilitation team?
6. Tell me about your experience after the injury and during rehabilitation.
7. Tell me about your experience after the rehabilitation.
8. What is the most difficult for you now, after the rehabilitation?
9. Describe how it's like dealing with your family member that has a traumatic brain injury.
10. Reflect on your views of the future with regard to your family member with a traumatic brain injury.

We have now come to the end of our interview. Thank you once again for participating in this study. Do you have any questions or concerns?

APPENDIX 4:
DECLARATION OF EDITING AND PROOFREADING