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Caregiving of Adults with Acquired Brain Injury (ABI):
A case study of mothers' perspectives.

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STNING004

Research report submitted in partial fulfilment of MSc OT by coursework

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DECLARATION

I, Inge Steinhoff, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that I have used the UCT Harvard system of referencing. I declare that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree at this or any other university.

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I declare that the above thesis is my own unaided work, both in concept and execution, and that apart from the normal guidance from my supervisor, I have received no assistance except some limited writing support (structure, language usage & style only) and editing of draft versions and the final document as submitted, from Dr Gudrun Oberprieler (www.academicssupport.co.za).

Signature:

Date:

DEFINITIONS OF TERMS

Acquired Brain Injury (ABI): 'Damage [that] may be caused traumatically (i.e. by motor vehicle collision, fall, assault, sports injury) or through a medical problem or disease process which causes damage to the brain (i.e. anoxia, aneurysm and vascular malformations, brain tumours, encephalitis, meningitis, stroke with cognitive disabilities)' (Toronto Acquired Brain Injury Network, 2011).

Being: 'The essential nature or interests that drive individuals' (Wilcock, 2006:113-145).

Brain Injury Survivor (BIS): 'Someone who sustained a non-fatal brain injury that causes some loss of functionality' (definition by author).

Doing: 'Actual engagement in occupation, experienced as embodied action or mindful activity unfolding through time' (Hocking, 2000:148).

Environment: 'Particular physical, social, cultural, economic, or political features within a person's context that affect the motivation, organisation, and performance of occupation' (Blesedell Crepeau, Cohn & Boyt Schell, 2009:1157).

Maternal Caregivers: 'Mothers who help or care for [young] adults after traumatic brain injury (TBI)' (Wongvatunyu & Porter, 2005:48).

Occupation: 'Occupation is an organized form of human endeavour having a name and associated role title' (Hagedorn, 1995:299).

Occupational Balance: 'Balance of engagement in occupation that leads to well-being. For example, the balance may be among physical, mental, and social occupations; between chosen and obligatory occupations; between strenuous and restful occupations; between doing and being' (Wilcock, 2006:343).

Occupational Being: The human need for occupation (Wilcock, 1993:17-24).

Occupational Imbalance: 'A lack of balance or disproportion of occupation resulting in decreased well-being' (Wilcock, 2006:343).

Occupational Performance: 'The ability to choose, organize and satisfactorily perform meaningful occupations that are culturally defined, age appropriate for looking after oneself, enjoying life and contributing to the social & economic fabric of the community' (Canadian Association of Occupational Therapy, 1997).

Occupational Role: 'The behavioural expectations that accompany one's occupied position or status in a social system' (Neistadt & Blesedell Crepeau, 1998:527).

Occupational Well-being: 'A perceived state of harmony in all aspects of one's life' (Orem, 1985:34).

Primary Caregiver: 'The one person most responsible for providing care to the [older] adult on a daily basis' (Stephens, Franks & Townsend, 1994, as quoted by Dellmann-Jenkins, Blankemeyer & Pinkard, 2000:177).

Resilience: 'The capacity to recover quickly from difficulties; toughness (Oxford Dictionary).

Role: 'A set of expectations placed on an individual in a particular social context that become part of [his] her identity and influence [his] her behaviour' (Creek, 2002:588).

Second-Order Patients: Caregivers who experience 'tremendous psychosocial and physical impact, while providing care' (Pickens, 2010:236).

Terminology: In most of the literature reviewed for this study, authors either wrote on individuals with traumatic brain injury (TBI) or on individuals who sustained a cerebrovascular accident (CVA). The term 'acquired brain injury' (ABI) incorporates both CVAs and TBIs and is used in this study in accordance with the literature (Zoltan, 2007:Preface; Gan and others, 2006:587; Braine, 2011:156; Toronto Acquired Brain Injury Network, 2005).

The term 'maternal caregiver' is used predominantly throughout the research report. It is used to refer to the mothers who act as caregivers to adult ABI survivors and incorporates terms such as 'caregiver' and 'mother' that have been used in literature reviewed for the study (Wongvatunyu & Porter, 2005:49; Howard, 1994:107; Sales and others, 2004:218).

University of Cape Town

ABSTRACT

Background: The care of ABI survivors has a significant impact on the health and wellbeing of the caregivers who, according to the literature, are in the majority of cases their mothers. Occupational therapists working with ABI survivors liaise closely with their primary caregivers who may present as 'second-order patients' seeking support for the challenges of the caregiving role. Literature suggests that attending to the needs of maternal caregivers as potential 'second-order patients' promotes the provision of good care and the attainment of positive rehabilitation outcomes for the ABI survivors. **Research problem:** Paucity of information about and understanding of the experience of maternal caregivers of adult children who are brain injury survivors limits the contribution, which occupational therapists can make in working with maternal caregivers as second-order patients. **Research Purpose:** To increase the knowledge base for incorporating maternal caregivers as second-order patients in occupational therapy and other interventions for adult ABI survivors. **Research Aim & Objectives:** The aim of this study was to explore the perceptions of maternal caregivers of ABI survivors. The objectives were to describe what mothers think caregiving as an occupation entails and how they, as occupational beings, perceive the caregiving role. **Research Design:** A collective case study was conducted, incorporating four cases of maternal caregivers identified through purposive sampling. **Research Methods:** Face-to-face in-depth interviews were conducted until data saturation was reached. Approximately two hours of interview data was collected from each participant. Data was captured via audio recordings. Following each interview, the researcher wrote up field notes and interpretative accounts. **Data analysis:** Transcription of recorded data enabled the researcher to do an interpretive inductive within and cross-case analysis. **Findings:** One theme 'Being the Holding Environment'; two categories 'Maternal Caregivers as Containers' and 'Maternal Caregivers as Conductors' and four subcategories 'Accepting States'; 'Ambivalent States'; 'Knowing how to' and 'Not knowing how to' emerged. Maternal caregivers transitioned between states of acceptance and being ambivalent about their acquired role. They oscillated between 'knowing how to' and 'not knowing how to' perform the occupation of caregiving. **Conclusions:** Transitions between caregiver strain and constructive control of caregiving create particular tensions, which warrant attention when considering mothers as second-order patients.

Keywords: Acquired Brain Injury (ABI) survivors; maternal caregiving; second-order patients; attachment theory, caregiver benefits; role demands, adult: 18+ years

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LIST OF ABBREVIATIONS

- ABI:** Acquired Brain Injury
CVA: Cerebrovascular Accident
CVD: Cardiovascular Disease
TBI: Traumatic Brain Injury

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CHAPTER 1: INTRODUCTION

1.1 Background

The onset of an acquired brain injury (ABI) generally occurs without warning and has a huge impact on the ABI survivor and his or her family (Engström & Söderberg, 2011:253). According to Hafsteinsdóttir and others (2011:9), family members often become the main caregivers of the ABI survivor and are faced with this new role without warning. As the brain injury occurs so suddenly, the acquisition of the caregiver role is very immediate. Family members often lack practical caregiving skills, which can lead to feelings of 'not-coping', stress, and feelings of being overburdened with additional role demands. Wongvatunyu and Porter (2005:48) state that 'although spouses have been primary care givers for about 25% of survivors, mothers have filled that role for about 50% of survivors'. Literature on maternal caregiving of adult ABI survivors is scarce especially in occupational therapy, a critical rehabilitation service provider for persons with ABI.

This study was motivated by the personal clinical observations of the researcher as an occupational therapist at a private rehabilitation facility for adult neurological conditions where the needs of maternal caregivers regularly surfaced as a priority service area. Clinical experience suggests that mothers are resilient in being caregivers. They reported devoting themselves tirelessly and altruistically to the care of their adult son or daughter. At the same time, they reported and showed signs of experiencing stress due to the demands of suddenly having to care for an adult child who prior to the ABI was leading an independent life. The mothers appeared to be pushing themselves to fulfil their caregiving role (Pickens, O'Reilly & Sharp, 2010:237); this raised questions about the impact of this unexpectedly acquired occupation on their own health and well-being. Pickens, O'Reilly and Sharp (2010:236) suggest that 'caregivers should be thought of as "second-order patients in their own right"' due to the intense demands that being a caregiver places on them. Stress and the caregiving burden has been extensively described in the literature (Gan and others, 2006; Kreutzer and others, 2009:239; Pickens O'Reilly & Sharp, 2010:236). The role that family members play in the rehabilitation of the ABI survivor is crucial; especially the strain on the caregiver due to the multitude of caregiving tasks also requires consideration in the rehabilitation process. (Kreutzer and others, 2009:545). In agreement with Pickens, O'Reilly and Sharp (2010:239), the researcher believes that as skilled

professionals, occupational therapists are able to assess caregivers' own needs and assist them with caring for themselves within their caregiver roles. The focus of this study was therefore identified as a response to the absence of occupation-focussed literature on maternal caregiving in the context of ABI.

1.2 Acquired Brain Injury (ABI)

The increasing prevalence of ABI cases in South Africa points to the importance of rehabilitation professionals in general and occupational therapists in particular learning more about the needs of maternal caregivers. The main causes of ABIs are cardiovascular accidents (CVAs) and traumatic brain injuries (TBIs). CVAs may occur as a result of cardiovascular diseases (CVD) or as a result of TBI. The prevalence of CVDs is increasing in developing countries including South Africa (Mbewu & Mbanya, 2006:309-310). According to Mbewu & Mbanya (2006:305), CVAs account for 7% of deaths in South Africa. Strokes [CVAs] are the most common cause of disability in the developed world (Hafsteinsdóttir and others, 2011:14). CVAs can be lifestyle related, which affects predominantly the older part of a population. CVAs in young adult populations can be caused by aneurysms or infectious diseases of the brain (for example positive HIV-status and AIDS). According to Hoffmann and others (2000:233), an 'association between HIV and cryptogenic stroke' exists, with CVAs found to be co-morbid with a positive HIV status in the South African context. Although the benefits of anti-retroviral medication enable people to have a good quality of life in spite of HIV infection, disability associated with a positive HIV status is multi-dimensional, and 'the dimensions of disability' (Hanass-Hancock, 2009) include not only physical impairments but also emotional challenges as well as social stigma for people living with HIV/AIDS (Watson & Fourie, 2004:46-47). In such cases mothers can be faced with complex demands - physical as well as emotional and psychological - on their role as caregivers when caring for a son or daughter who has a life-threatening disease (HIV/AIDS) in addition to an ABI. Furthermore, the socio-political environment of low-income peri-urban areas in Cape Town can make it difficult if not impossible to obtain the necessary support from the healthcare system due to financial constraints and lack of access to service providers (Nixon and others, 2011:41; Weskamp & Ramugondo, 2004:161).

TBIs are the other main cause of ABIs. The Kwa-Zulu/ Natal Department of Health (2009) estimates that around 89,000 new TBIs occur annually in South Africa. A national study of

the epidemiology of brain or head injuries has never been conducted in South Africa (Ormond-Brown, 2006:34). However, a survey conducted in Johannesburg from 1986 to 1990 revealed that the annual incidence of new TBIs in Johannesburg was 316 per 100 000 of the population (Ormond-Brown, 2006:34). Against this background it can be argued that there is a growing need for comprehensive rehabilitation services that address not only the needs of ABI survivors but also those of the affected families and in particular those of the maternal caregivers.

1.3 Caring for persons with ABI

Braine (2011:157) indicates that ABI affects the survivor him-/herself as well as his/her family profoundly, with a high likelihood that the experience will have a life-long negative impact on the quality of life of the ABI survivor and his/her family.

Many mothers are acting as caregivers of a child who has become a disabled adult ABI survivor, but little is known about how they execute and experience the acquired occupation of caregiving. Although extensive literature exists about caregiving in general (Lin, 2011:96; Moghimi, 2007:269-279; Coutinho, Hersch & Davidson, 2006:47-61; Jones, Hocking & Wright-St. Clair, 2010:4-13), the occupational therapy literature about the needs of mothers associated with the occupation of caregiving is limited. Knowing more about what this occupation entails and how mothers perceive their acquired caregiving role will inform the contribution that rehabilitation can make towards addressing caregivers as second-order patients in the context of ABI.

Statistically, mothers are more likely the ones fulfilling the role of caregivers for ABI survivors: 'although spouses have been primary caregivers for about 25% of survivors, mothers have filled that role for about 50% of survivors' (Wongvatunyu & Porter, 2005:48). It appears to be a general expectation across cultures that mothers are the primary caregivers of their children (Du Toit, 2010:71). Mothers are caregivers by virtue of their socio-biological position. To care for their children is what is naturally expected of them and their role of being a mother (Heard and Lake, 1997:3). Similarly, Porter & Kelso (2008:xi) state that 'mothering impacts on women in every area of their lives. Once a woman becomes a mother, she is a mother for the rest of her life'.

In the occupational therapy and occupational science literature maternal caregiving or, in fact, caregiving in general has received little attention to date. Whalley Hammel (2009:10) explains that the lack of awareness amongst occupational therapists in this area may be the result of the commonly used definition of 'occupation' that still dominates most theoretical concepts in occupational therapy. 'Occupation' is usually defined by categorizing activities that people engage in into three different areas, namely 'self-care', 'productivity' and 'leisure'. Caregiving does not fit into any of the above categories, which is a concern when wanting to incorporate caregivers into occupational therapists' service provision. The researcher thus sees the need to include a fourth category, 'care of others' into the definition of occupational therapy.

Another definition of 'occupation' provided by Hagedorn (1995:299) advises that occupation is 'an organized form of human endeavour having a name and associated role title' and therefore includes caregiving as an occupation. However, the understanding of the categories that make up the definition of occupation as stated above may prevail though in the practice of occupational therapists. The occupation of mothering includes what a mother does (doing), how a mother sees herself (being), and how the experiences of motherhood affect future participation in a motherhood role (becoming). The doing, being and becoming shape the occupational identity and contribute to the journey of understanding of 'who one is and who one wishes to grow to be' (Del Fabro Smith and others, 2011:40). Little is known about the perceptions of maternal caregivers of ABI survivors about caregiving as an occupation and about the implications of this role for their doing, being and becoming.

Providing the best possible care or making effective decisions for their loved ones is not something that ABI caregivers automatically know how to do. Being unfamiliar with the medical, behavioural and functional implications of ABI can leave them feeling frustrated and helpless (King & Quill, 2006: 704). Furthermore, mothers providing care to ABI survivors may experience a lack of occupational balance (Wilcock, 2006:343) and wellbeing due to the high caregiver demands. Providing for the needs of the ABI survivor in addition to attending to other family members' needs can place a tremendous strain on the mothers. They may also have to contribute to the family's income and maintain the household amongst other possible role demands put on them.

The rehabilitation outcome for the brain injury survivor can be negatively affected if the caregiver finds herself stressed and in compromised health, whether linked to the caregiving role or not. The literature shows that good health and wellbeing of the caregiver positively influence the health and wellbeing of the brain injury survivor (Verhaeghe, Defloor & Grypdonck, 2005:1008; Kreutzer and others, 2009:536; Gan and others 2006:587; Engström & Söderberg, 2011:258). Sullivan and others (2011:643) advise that emotional and cognitive development is linked to the quality of care received from the mother. They are referring to a sculpting of the brain. In reference to adult ABI survivors it emphasizes the mothers' possible impact on the recovery of the injured brain of their adult children. The need for the maternal caregiver to care for herself is therefore crucial. Occupational therapists and other rehabilitation providers would benefit from attending to the needs of caregivers as potential second-order patients who play a pivotal role in promoting the healthy adjustment of the ABI survivor throughout the rehabilitation process.

1.4 Problem statement

There is little information in the professional literature about the perceptions of maternal caregivers of adult ABI survivors with regards to how they execute and experience the acquired occupation of caregiving. The insufficient representation in the occupational therapy literature may curtail the attention that occupational therapists give to the needs of maternal caregivers of adult ABI survivors as second-order patients.

1.5 Research question

How do maternal caregivers of adult ABI survivors perceive the occupation of caregiving and their acquired caregiving role?

1.6 Purpose of the study

The purpose of this study is to increase the knowledge base for incorporating maternal caregivers as second-order patients in occupational therapy neurological rehabilitation. Occupational therapists may benefit from knowledge on how maternal caregivers perceive the occupation of caregiving in order to integrate this into their clinical approach when dealing with brain injury survivors and their caregivers. Through including maternal caregivers of adult ABI survivors into the therapy sessions the knowledge about how they perceive their caregiving role and the occupation of caregiving can help understand their role demands better. Family meetings can be informed by the knowledge generated and maternal caregivers can generally be better understood within the service provision of occupational therapy to the client and the family, especially to the mothers.

1.7 Aim of the study

The aim of this study was to describe the perceptions of maternal caregivers, i.e. mothers as primary caregivers of their adult children who are ABI survivors, and about caregiving as an occupation.

1.8 Objectives of the study

- To describe how mothers of ABI survivors experience the caregiving role.
- To describe what mothers of ABI survivors consider the occupation of caregiving to entail.

1.9 Assumptions

Based on the literature and the clinical work conducted by the researcher as therapist, the following assumptions were posed:

- Caregivers experience negative life change after an acquired brain injury affected their adult son or daughter (Wallace and others, 1998:485).
- Mothers providing care to ABI survivors experience a lack of occupational balance and wellbeing due to 'role overload' (Pickens and others, 2010:235; Gan and others, 2006:595).
- Occupational imbalance can lead to emotional problems such as stress and anxiety (Kreutzer, 1994:197; Hafsteinsdóttir and others, 2011:1).
- While maternal caregivers may experience occupational imbalance in meeting the needs of the ABI survivor, they do not always perceive this as a burden but may have feelings of satisfaction in performing this role (Hanks, Rapport & Vangel, 2007:43; Whalley Hammel, 2009:10).
- Mothers may interpret the brain injury survivors' level of impairment as a sign that their caregiving skills are not adequate (Hanks, Rapport & Vangel, 2007:41) or as an indication that they have failed as caregiver (Hanks, Rapport & Vangel, 2007:51).

1.10 Summary

This chapter has given an introduction to the research topic and study population, providing background information about ABI and its impact on primary caregivers, which, according to the literature, is usually the mother. It has been argued that more understanding is needed about the ways in which mothers execute the occupation of caregiving and how they perceive the caregiving role. The importance for occupational therapists and other health practitioners to learn more about maternal caregivers' needs when acquiring the role of caregiver of adult ABI survivors has been highlighted. An explanation was provided for how this study arose out of the clinical observations made by the researcher. It was pointed out that although maternal caregivers show resilience in their occupation of caregiving, they also report a high level of stress which can impact on their health and well-being. Furthermore, the impact that the caregiver's health and well-being has on the rehabilitation potential of the ABI survivor was emphasized, suggesting that caregivers may need to be viewed as 'second-order patients' deserving focussed support from rehabilitation professionals. The chapter concluded with a summary of the research problem, the purpose, aim and objectives of the study, and assumptions made.

CHAPTER 2: LITERATURE REVIEW

2.1. Introduction

The literature review presents an exploration of studies on caregiving of adult brain injury survivors. The impact that caregiving has on the mothers and families of the ABI survivor has been the main interest in the reviewed literature. A differentiation was made between caring for a family member as opposed to doing care work; articles that investigate caregivers doing care work have been excluded. Literature on 'burden of care' was selectively included as here the focus is predominantly on the negative impacts that caregiving has on the non-related caregiver and provides restricted insight into the complexity of the maternal caregiving role and possible positive outcomes of this occupation. In the past ten years there has been an increase in the body of research on the impact that ABI has on families but this area still remains under-investigated. Most of the research focuses on the brain injury survivor. This trend can be observed particularly in nursing research (Wongvatunyu & Porter, 2005; Anderson, Parmenter & Mok, 2002; Verhaeghe, Defloor & Grypdonck, 2005). Increased research on ABI and caregiving has been conducted in the rehabilitation sciences (Visser-Meily and others, 2005; Hanks, Rapport & Vangel, 2007). In occupational therapy and occupational science literature little has been written on maternal caregiving. The literature that was found on caregiving focuses on caregiving to either spouses or children, but no articles could be located within occupational therapy or occupational science literature that focus on maternal caregiving of adults with ABI.

2.2 Care implications of Acquired Brain Injury (ABI)

Even though the advancement of medical knowledge and assistive technology have contributed to a longer life span of people post ABI, ABI survivors are often faced with a life that is marked by physical, cognitive, emotional, and behavioural difficulties and are dependent on therapy in the short and long term (Ghajar, 2000:923). Families usually have to get involved in the different areas of the ABI survivor's everyday life. This can include activities of daily living, structuring, planning and organizing the ABI survivors' life, as well as assisting with physical and cognitive exercises to promote rehabilitation (Degeneffe, 2008:10). All of the above problems can occur within a wide range between mild, moderate to severe impairment, depending on the impact and severity of the brain injury.

Physical impairments can range from hemiparesis, muscle spasticity, to perceptual deficits often related to vision and other sensory deficits, i.e. position of body in space, paraesthesia, perception of sound, temperature etc. (Degeneffe, 2001:258). Muscle spasms can present a risk for contractures and require a high level of care such as stretching the limbs and re-positioning the ABI survivor 2-3 hourly to avoid these as well as to prevent bed sores. Emotional problems inform behavioural problems which can present as depression, anger, anxiety, low levels of self-esteem, and apathy (Degeneffe, 2001:258). Cognitive problems frequently occur in the form of memory loss, attention deficit, poor concentration and processing deficits, amongst many others (Degeneffe, 2001:258). Any of these problems can present the caregiver with a high demand on their physical and emotional involvement to support and often has a great impact on the caregiver's wellbeing. This impact wears down on the caregiver and should be attended to by the rehabilitation team as it is of utmost importance for the caregiver to maintain his/her health and wellbeing in order to support the ABI survivor and to maintain his/her other roles.

In the everyday life of a hospital or rehabilitation facility the clinical staff often barely has enough time to adequately attend to the needs of ABI survivors, let alone to address the needs of their families. Kreutzer and others (2009:535) suggest that as a result of these constraints, clinical staff and therapists often pursue the primary goal of assisting the brain injury survivor to regain some functional capacity. The service provision of occupational therapists in clinical practice is often limited to facilitating training of activities of daily living (ADL) or impairment focussed, component-based interventions or assessing the client for his needs regarding assistive devices. Therapists have little opportunity to address the wider occupational needs of survivors, and even less opportunity to support and guide family members who take on caregiving responsibilities. The wider needs of survivors amongst others are: time for neuro-behavioural recovery, discharge planning as well as facilitating emotional support and assist with community reintegration (Kreutzer and others: 2009:535). According to Wongvatunyu and Porter (2008:315), two thirds of TBI survivors live with their families who are responsible for their long-term care. Kreutzer and others (2009:535) found that nine out of ten patients who are discharged to their homes require a family member to act as caregiver for many years, although they may never have received any guidance to help them adapt to this kind of situation. Kreutzer and others (2009:535) further emphasize the link between quality of care and the need for the

families to cope with the new tasks that they are facing. The length of hospitalization of the ABI survivor does not allow for families to recover from the shock caused by the initial injury, let alone prepare for the complex demands of provision of care that may be required of them. Hafsteinsdóttir and others (2011:16) have indicated that the lack of sufficient education made available to stroke survivors and their caregivers can result in 'misconceptions, anxiety, fear, poor health status and emotional problems like depression'.

2.3 Physical tasks of caregiving

A large number of ABI survivors present with physical, cognitive, emotional, and behavioural problems as a result of the incident (Blake, 2008:263), and rehabilitation is often a long-term process. Family members who become caregivers usually have little or no training in nursing nor a medical or psychology background. Regardless, they are faced with the multi-faceted aspects of assisting the ABI survivor in his/her daily life (Pickens and others, 2010:238). According to Degeneffe (2008:11), the caregiving tasks can be divided into 'affective and instrumental social supports'. Affective support consists of the emotional assistance that is required to support an ABI survivor on his/her long road to recovery. Being with the ABI survivor in an encouraging and supporting way is the core of this support that can consist of motivating and uplifting the care recipient to participate in activities and exercises, as well as calming the ABI survivor down when upset or agitated (Harvard Mental Health Letter, 2009). Instrumental support speaks to the physical tasks of caregiving such as 'completing chores, running errands, handling finances and preparing food' (Degeneffe, 2008:11).

2.4 Caregivers' role demands: health and well-being

The impact that an ABI survivor has on the family is vast. Physical, emotional, cognitive and behavioural problems amount to a high level of care in one way or another. The caregiver is suddenly faced with having to learn and master physical handling techniques of the brain injury survivor while trying to protect her own physical health and wellbeing. Cognitive, emotional and behavioural problems can be an extreme stress factor for the caregiving mothers as they have to remain patient, understanding and caring 24 hours per day, every day. This can be a great stressor and present a burden for the caregivers (Visser-Meily and others, 2005:257). The impact that these problems have on the family functioning is evident from the findings of Verhaeghe, Defloor and Grypdonck (2005:1009) who stated that 30% to 50% of couples get divorced within eight to ten years following the injury of a family member. Gan and others (2006:587) emphasized that the rehabilitation outcome for brain injury survivors is closely linked to the health of the family or support structure. Kreutzer and others (2009:536) stated more specifically that the quality and extent of recovery of the brain injury survivor is directly linked to the ability that a family shows in coping with the stress associated with caregiving. This highlights the importance of incorporating the caregiver into the occupational therapy service provision as second-order patients. As their health and well-being is directly linked to the health and well-being of the ABI survivor, occupational therapists can positively impact on the maternal caregivers' health through a wider scope of service provision. As mothers most often become the main caregivers, it is of value to consider the findings in the literature stating that many of the mothers who engage in the occupation of caregiving present with psychological distress due to the impact that the provision of care has on them (Kreutzer, Gervasio & Camplair, 1994:197). Wallace and others (1998:485) claim that 67% of caregivers who were either spouses or parents indicated a negative life change one year post injury. A significant factor that is putting strain on the maternal caregivers is assumed to be the lack of balance in their lives. Wilcock (2006:343) emphasizes in her definition of occupational balance the 'need for balance of engagement in occupation that lead(s) to well-being. For example, the balance may be among physical, mental, and social occupations; between chosen and obligatory occupations; between strenuous and restful occupations; between doing and being'.

The role demands of being a caregiver and performing the occupation of caregiving are very high and are commonly referred to in the literature as 'caregiver burden' (Lehan and others, 2012:87-95; Moghimi, 2007:269-279; Brachtesende, 2004:13-7; Chronister & Chan, 2006:190-201). As indicated previously, literature about burden of care has not been extensively reviewed because of its exclusive focus on burden instead of also considering the benefits of caregiving. Caring for a loved one and more specifically one's own child contains many aspects that are not simply classifiable as 'good' or 'bad'. Conversely, caregivers may perceive their caregiving responsibilities as rewarding and empowering (Schwartz and Gidron, 2002, in Green, 2007:151). Occupational therapists need to be aware of the multitude of demands maternal caregivers may experience that are interlaced with their own understanding and desires regarding their roles as mothers. They may experience burden but at the same time they are providing care to their child and contribute to his/her recovery and the attainment of positive rehabilitation outcomes.

2.5 Burden of care

Caregiving of ABI survivors place a complex demand on the caregivers, and burden of care is likely to be perceived at some point in time. It is an occupation that is often acquired without warning and always lies beyond the caregivers' control. The new role often comes with many challenges that are not only constituted by the physical impact of provision of care but also by behavioural changes of the brain injury survivor. The lifestyle of the caregiver is often affected by a lack of social contacts as well as the lack of pursuing own interests and activities (Hanks and others, 2007:43). As caregiving can be a very time-consuming task that requires a lot of patience and strength (emotional and physical) from the caregiver, it is crucial that the mothers have a support system in place that not only assists them with caregiving tasks but attends to their emotional needs as well. In response to this, research has alerted to the caregivers' perception of burden and depression at different times after the brain injury (Wells and others, 2005:1106).

Caregivers spend a substantial part of their days doing, consisting of practical assistance, being with, talking or other household activities related to caring for the ABI survivor (Pickens and others, 2010:238). But care is usually not just required by the ABI survivor but by other family members as well, with the caregiver also having to attend to household chores, friends and the self (Lin, 2011:102). Due to the demands of having to attend to

multiple roles, receiving support is of utmost importance for the mother's health and well-being and can reduce the burden of caregiving (Wells and others, 2005:1113).

However, by foregrounding the presumed negative aspects of caregiving, insufficient attention is given to highlighting its positive aspects. Some of the literature indicates that families experience positive feelings associated with caregiving (Wells and others, 2005:1113).

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2.6 Positive aspects of caregiving

Wells, Dywan and Dumas (2005:1107) stated that life satisfaction did not decrease due to the demands of caregiving; rather, 60% of caregivers who participated in a study expressed more positive than negative feelings about being caregivers. However, caregiving burden is generally assumed, without considering the possibility of mothers experiencing positive aspects of their role. Emotional distress of mothers of children with disability is constructed societally with mothers being regarded as victims (Green, 2007:161). This is clearly based on societal assumptions and informed by a generally negative perception of disability. According to Donovan and Corcoran (2010:590) who have done research on the caregivers of people who suffer from dementia, many occupational therapy interventions for caregivers are aimed at reducing the negative consequences of caregiving. They suggested that occupational therapists are skilled to administer interventions that support caregivers by focussing on the positive components of caregiving (Donovan & Corcoran, 2010: 590). In doing so, they can 'promote occupational performance of the caregiver and care recipient' (Donovan & Corcoran, 2010:593). Families and particularly mothers show a high level of resilience in enduring the hardships of the caregiving demands. One of many possible explanations for that can be found in a study by Engström and Söderberg (2011:258) who stress the fact that people are interconnected by emotional ties and that these are fundamental to being human. Families are motivated to care for a brain injury survivor because they feel it is beneficial, not just for the care recipient but for themselves in return. In short, the literature suggests that any intervention with caregivers should focus on the total caregiving experience, inclusive of a range of both challenges and advantages.

2.7 Caregivers as second-order patients

Foregrounding caregivers as second-order patients does not mean that they are pathologised, but rather that their needs are also addressed as part of the recovery journey of the ABI survivor. Pickens, O'Reilly and Sharp (2010:236) promote addressing caregivers as 'second-order patients in their own right' due to the impact that caregiving can have on their own lives. An additional emphasis is on the possible occurrence of 'role overload' that, according to Pickens, O'Reilly and Sharp (2010:235), can cause occupational imbalance and impact negatively on the entire family. Families are in many cases the only resource for the brain injury survivor, and if caregiver needs are not met, they may experience difficulties to meet the needs of the brain injury survivor or will only be able to do so in a compromised way. Consequently, there are expectations of maintaining the same role before and after brain injury towards the mothering role in the event of a medical diagnosis (Fujii, 2005:54). Subsequently, the mother begins to feel that she alone can protect her child and ultimately takes on sole responsibility as caretaker. This self-imposed role expectation places a big burden on the maternal caregiver with regards to time management, restrictions on own personal time and coping with stress and anxiety, worry and doubt. As a result, occupational imbalance may occur which can lead to ill-health of the caregiver and therefore negatively impact on the care recipient. Engström and Söderberg (2011:258) propose that 'close relatives of people with TBI need support from healthcare providers for them to be able to manage to support the person with a TBI'.

The everyday life of a maternal caregiver often evolves largely around the provision of care to the ABI survivor. In order to achieve and maintain positive rehabilitation outcomes for the ABI survivor it is crucial that the maternal caregivers are being supported in some way to be able to support and nurture their ABI survivor son or daughter (Visser-Meily and others, 2005:257). Verhaeghe, Defloor & Grypdonck (2005:1008) emphasized that the better family members are adapted to the new situation of caring for a brain injury survivor, the better the potential for adaptive functioning of the brain injury survivor. Little information is however available on the perspectives of maternal caregivers regarding the demands and impact of caregiving as an acquired occupation, making it difficult for rehabilitation professionals to formulate their interventions for these second order patients. Occupational therapists can assess caregivers' needs and together with them

facilitate a healthy, balanced lifestyle, incorporating the role of being caregivers whilst maintaining previous roles and occupations.

2.8 Caregiving as occupation

Clark (1997:86) emphasizes Wilcocks' theory of the biological need for occupations. When considering people as occupational beings, it is crucial to consider the type and impact of occupation under health promoting criteria.

Occupations should be meaningful, purposeful and health promoting (Clark, 1997:86). Caregiving is a major occupation for the research participants and is no doubt purposeful, although the meaning cannot be assumed by health care providers. Meaning differs individually and depends on a multitude of factors. Even though the occupation of providing care to an adult ABI survivor may be meaningful to the caregiver - in fact, Bunting proclaims that caring 'is the most deeply engaged experience of our lives' (2004:322) -, it needs to be carefully investigated in each individual case.

Performing caregiving tasks, such as washing, dressing and feeding the child, require time, patience and good organisational skills with regards to balancing other role demands as indicated previously. If the demand of one particular task outweighs all other tasks, occupational imbalance (Townsend & Wilcock, 2004) can occur. The tasks that characterize the occupation of caregiving are physically, mentally and emotionally tiring and require an individual in-depth investigation to determine if the occupation has meaning and is health promoting. Some caregivers manage the role demands better and are able to perform the caregiving occupation more successfully than others. Reasons may be that they may have better strategies or coping skills. A significant factor that influences the balance and the state of being capable or knowing how to do something is occupational resilience (Canadian Association of Occupational Therapy, 2009). According to Mannion (1996:14), resilience describes 'how family members experience a process of constructive change and growth in response to serious [...] disorder in a loved one'. For occupational therapists working in the field of neurology it is important to recognize mothers' resilience to conquer adversity by acknowledging the existence of burden and painful feelings (Abelenda 2003:29).

2.9 Summary

A review of the literature has shown that while caregivers report strain from carrying out the caregiving occupation, they also indicate positive aspects of care. The literature also highlights how little occupational therapists and other health professionals know about the perceptions of maternal caregivers and their needs. Pertinent to the research question is the fact that the literature endorses that caregivers should be incorporated into occupational therapy interventions as second-order patients. Occupational therapists could enhance maternal caregivers' well-being with a resulting benefit to the health of the ABI survivor. The knowledge base required for occupational therapists to provide such a service is, however, insufficient and requires further research.

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CHAPTER 3 : METHODOLOGY

3.1 Introduction

This chapter describes the qualitative nature of the study. It explains the research design, the methodology used, and how the data analysis was performed. The research participants are introduced in this chapter, and issues of trustworthiness and ethical considerations are covered.

3.2 Design

A qualitative descriptive research design was chosen for this study because of the inductive, exploratory nature of the inquiry. Cook (2001:4) emphasizes that occupational therapists and qualitative researchers understand that the clients' or research participants' expertise often places them in the position of a learner (rather than an expert) with regard to a certain health condition. The four participants of this study were considered 'experts' in the caregiving role of ABI as a health condition. They were therefore able to give a qualitatively descriptive and rich personal account of their individual experiences within their specific contexts.

3.3 Theoretical premises

The theoretical premises of this study are derived from three different sources. The first is the field of occupational therapy medical rehabilitation, and the second is occupational science. The American Occupational Therapy Association (AOTA: 2012) defines occupational therapy medical rehabilitation as 'an individualized evaluation, during which the client/family and occupational therapist determine the person's goals. A customized intervention to improve the person's ability to perform daily activities and reach the goals and an outcomes evaluation to ensure that the goals are being met and/or make changes to the intervention plan'. The occupational therapy profession promotes health by enabling people to perform meaningful and purposeful occupations (Wilcock, 2006:5), with caregiving being a major occupation for the research participants. Theoretical premises of occupational science, namely occupational imbalance (Townsend & Wilcock, 2004) and occupational resilience (CAOT, 2009) were used as conceptual frames for explaining maternal caregivers' perceptions of caregiving as occupation. The third framework that is

being drawn on to embed the findings is attachment theory as defined by Bowlby (2005), as this is an important factor in the relationship between mothers and their children.

3.4 Methodology

A collective case study methodology was used which is based on the investigation of a phenomenon through studying different cases (Stake, 2006). It can be understood as an instrumental study, extended to more than just one case (Stake, 1998). In an instrumental case study, some cases are more useful than others. Typical cases can illustrate the phenomenon under study well, but atypical cases often bring out aspects that may be overlooked in typical cases.

The mothers gave a personal account of their individual experiences within their specific contexts. The interest in each case was intrinsic 'because we need to learn about that particular case and not a general problem' (Stake, 1995:3). At the same time, the multi-case researcher starts with studying cases 'in terms of their own situational issues, interprets patterns within each case, and then analyzes cross-case findings to make assertions about the binding' (Stake, 2006:10). Commonalities and differences between the cases were extracted by within-case and across-case analyses. Patterns that emerged were theorised through occupational science and occupational therapy medical rehabilitation constructs (see 3.3 above).

3.5 Methods of data collection

3.5.1 In-depth interviews

Data was obtained through face-to-face in-depth interviews (Keen & Packwood, 2000:55; Rice & Ezzy, 1999:65; Taylor, 2005:39). The interviews were intended to obtain a personal story of each mother about how they perceive the occupation of caregiving and themselves as occupational beings carrying out the caregiving role. The uniqueness of each case was emphasized by adjusting the interview schedules according to the emergent stories. The interviews were conducted using a set of beforehand defined probing questions (Appendix D) that facilitated the provision of an unrestricted account of the impact of the son's or daughter's brain injury on the mother's life as an occupational being (Wongvatunyu & Porter, 2005:50). The intention of the researcher was to explore how participants 'convey understandings of their lives and social worlds through story' (Rule & John, 2011:80). The pre-set of probing questions was identified through a combination of clinical observations by the researcher of mothers of ABI survivors, and through a review of relevant literature. The probing questions were phrased to facilitate the mothers' ability to be introspective about their feelings, experiences, hardships and joys, i.e. their 'being' perspectives, associated with the 'doing' of the everyday caregiving activities and tasks (occupation).

3.5.2 Case and field notes

Field notes were written in a research journal immediately after the interview was completed as it could have been disturbing to do this while the interview was taking place. 'Important additional information such as [the researcher's] views and the respondent's nonverbals' (Thorpe & Holt, 2008:3) as well as the 'participant's behaviour and contextual aspects of the interview' (Mack and others, 2005:33) were part of the documentation. As suggested by Mack and others (2005:21), the notes were as detailed as possible so that they could be used as data in the analysis process. Field notes enrich thick descriptions of the individual cases. Key words and phrases were initially hand-written in a research journal using abbreviations where possible. Later they were written up with more detail and no abbreviations to ensure that the information was accessible to the reader and not to the researcher only.

Reflective journaling was used by the researcher to provide the reader with transparency regarding the nature of the research outcomes in this qualitative study. This will be further elaborated on in section 3.14.2 Credibility.

3.6 Pilot study

A pilot study was conducted prior to the main study as it assisted with refining the phenomenon under investigation (Todres, 2005:108). Seidman (2006:39) strongly advises the use of piloting of a proposed study to gain clarity about the interviewing process: 'the pilot can alert [the interviewer] to elements of their own interview techniques that support the objectives of the study and to those that detract from those objectives'.

Two research participants for the pilot were identified via purposive sampling, in the same way as the participants of the main study. Interviews were conducted with Babalwa and with Erika to pilot the interview schedule, and subsequently changes were made prior to conducting the main study. After transcription of the two interviews it became apparent that the information gathered was not saturated. This resulted in the researcher reflecting on her experience, discussing her findings with her supervisors and then revising the interview schedule, according to Seidman's suggestions regarding 'piloting your work' (2006:38-39). The prompting questions were refined accordingly, i.e. some questions were re-worded while others were added or deleted¹. The interview data from the interviews with the two pilot participants, Babalwa and Erika, was also used for the main study; in addition, second interviews with both participants addressed the changes made to the interview questions and ensured data saturation.

¹ See Appendix G for the probing questions for the pilot interviews, and Appendix D for the probing questions used in the main study.

3.7 Case sampling procedures

The study population consisted of four mothers who are caregivers of adult ABI survivors in the larger Cape Town area and who were identified to be representative for the study under investigation. The researcher contacted colleagues from different disciplines in the field of neuro-rehabilitation and identified four mothers from different socio-economic backgrounds. Furthermore, the time lapsed since onset of injury and the length of having been caregivers varied; this allowed for a broader spectrum of experiences of the caregiving role. Four cases were considered an appropriate sample size for this study due to the density of descriptive data which was likely to come forth from the individual interviews. As there is no need in qualitative research to do proportional sampling, it was anticipated that four cases would give sufficient information to identify commonalities between cases. All four mothers were fulfilling the role of primary caregivers as specified in the inclusion and exclusion criteria below. The research methodology assisted with gaining insight into the perspectives of mothers who are acting as caregivers.

The following criteria were used to identify maternal caregivers as eligible research participants:

Inclusion criteria:

The severity of the brain injury suffered by survivors was irrelevant for this study. Eligible for inclusion into this study were mothers who

- were primary caregivers of an adult son or daughter aged 18 years or older who sustained an ABI at least six months prior to the interview²
- lived with the brain injury survivor
- had minimum contact of five days a week, eight hours per day with the brain injury survivor
- were caring for a son or daughter who is gradually resuming a part-time productive occupation (maximum five hours per day)³
- were able to communicate their experiences in English⁴.

² This time frame indicated that the maternal caregiver had engaged in the caregiving occupation for a significant period of time.

³ If the ABI survivor would have been spending more than five hours daily at work or at university, the role of being a caregiver and performing the occupation of caregiving may have had less of an impact on the mother.

Exclusion criteria:

Not eligible for inclusion into this study were mothers of ABI survivors

- who were less than 18 years of age at the time of injury or who had sustained the injury at birth
- who were minimally impaired so that they were able to pursue full-time employment or full-time study
- who were living independently.

3.8 Sampling method

- Recruitment of participants was done via purposive sampling, i.e. typical cases 'representative of the population' under study were selected (Rule & John, 2011:22).
- Maximum variety was ensured by selecting participants that provide a wide variation in descriptive characteristics (Laliberte-Rudman and others, 2001). To assist the researcher with the selection of participants, the questions of the data sheets were discussed with the referral source (therapists, doctors) prior to making contact with the prospective participant. The criteria used were socio-economic backgrounds; time lapsed since injury and duration of the caregiver role.
- The participants were sourced from the private as well as the public sector of the health services. Two participants had their children at a public acute hospital at onset but had access to private rehabilitation facilities through their medical aids. Only one participant is paying privately for the rehabilitation services her son is receiving.
- Personal, telephonic and email contact with colleagues from different disciplines were used to inquire about potential research participants. The Occupational Therapy department at a government-funded teaching hospital in Cape Town that renders neurological public sector services was approached to obtain access to mothers whose children may not be part of any support groups or actively in therapy. Possible

⁴ The use of a translator was perceived as disruptive to the data collection environment and could have led to bias in the analysis process. The presence of a third person at the interviews could have been intimidating and disturbed the flow of an informal, in-depth interview. All the mothers were able to express themselves sufficiently in depth in English.

participants could have also been referred to the researcher by other sources such as support groups and community members, but this was not the case as the required number of participants was obtained through referrals by professional colleagues in the private rehabilitation sector as well as by one of the doctors at the hospital indicated above. The researcher was fortunate to recruit four eligible research participants in a short period of time as colleagues approached responded promptly. To ensure confidentiality, participants were only approached once their verbal consent was obtained by the referring person.

- The researcher contacted the prospective participants telephonically; information about the purpose of the study was given and an initial informal screening of their eligibility to participate was done (see inclusion and exclusion criteria, Section 3.7). The researcher asked about the time passed since the onset of injury, the duration of having been caregivers, the age of the ABI survivor at the time of injury, if the maternal caregiver was living with the survivor; it was also ensured that the survivors had not yet resumed their previous occupation or any other occupation that they engaged in for more than five hours per day.
- Once prospective participants agreed to take part, an appointment for the first interview was arranged and written informed consent was requested before the actual interview started. The information letter (Appendix B) and consent form (Appendix C) were given and explained to the participant to ensure that she was prepared for the interview that followed. It was offered that these be read to them, which two participants chose.

3.9 Introducing the participants

Table 3.1 provides a tabular summary of relevant demographic details of the four participants. More descriptive details about the participants follow in Section 4.2.

Table 3.1: Demographic details of participants

Participant ⁵	Babalwa	Erika	Sarah	Soliswa
Area	Gugulethu	Athlone	Camps Bay	Phillipi East
Age of mother	59	65	75	43
Marital status	Divorced	Married	Married	Married
Age of ABI survivor	32	40	55	19
Time lapsed since injury	11 months	4 years	17 years	18 months
Duration of caregiver role	11 months	3 years & 9 months	17 years	18 months
Number of other children/people in the home requiring direct/ indirect⁶ caregiving	0	1 child indirect care, 3 grandchildren, direct care	0	2, indirect care
Ages of other children⁷	40 (ih) & 34 (ih)	43 (oh), 39 (oh) & 37 (ih)	51 (oh) & 42 (oh)	25 (ih) & 21 (ih)
Number of people in the household	6	8	3	6
Family/ friends supporting	Sister, cousin, daughter's friends, neighbours	None	Daughter and husband	Husband

⁵ Pseudonyms

⁶ Direct care means: family members need to be assisted with execution of tasks related to activities of daily living

Indirect care means: family members who are attended to by providing meals, washing clothes, and providing a safe living environment.

⁷ ih = children who live in the home; oh = children who live outside of the home.

Formal support ⁸	None	None	None	None
Level of education	Grade 8	Grade 8	Matric	Grade 11
Employment	Self-employed	Pensioner	Pensioner	Unemployed
Income (per month)	ZAR 2200,-	ZAR 1550,-	ZAR 10.000 ,-	ZAR 1170,-
Health of caregiver	Arthritis in knees and hips – poor mobility	Hypertension	Mild heart attack, stent, high cholesterol	No problems reported

Table 3.2 Demographic information on ABI survivors

Name⁹	Nobanzi	Shawn	Robert	Thandiwe
Gender	Female	Male	Male	Male
Age at time of injury	31	36	38	18
Current age	32	40	55	19
ABI aetiology	CVA through aneurysm - intracranial haemorrhage	TBI through MVA, passenger in MV	TBI through MVA, pedestrian	CVA through blood clot

Key: TBI: Traumatic Brain Injury; MV: Motor Vehicle; MVA: Motor Vehicle Accident; CVA: Cardiovascular Accident

⁸ Counseling or advice received by the mothers.

⁹ Pseudonyms

3.10 Research environment

Three of the four interviews were conducted at the homes of the maternal caregivers. The homes that were visited were those of Erika in Athlone, Sarah in Camps Bay and Soliswa in Phillipi East. The interview with Babalwa from Gugulethu was done in the practice rooms of a colleague in Kenilworth, Cape Town, that were rented for the time as she felt more comfortable coming to meet the researcher there rather than at her own home. The research environment was chosen with particular care to ensure the privacy of the participants. The participants were made aware of the need to identify another caregiver for the duration of the interview as they would not be able to care for their son/daughter as usual. The researcher offered assistance to arrange a caregiver at the researchers' cost. All mothers were able to make other arrangements or the care was not needed for the duration of the interview. The participants came from different geographical and socio-economic backgrounds which could impact on their caregiving experience.

3.11 Data collection:

After telephonic contact had been made with the mothers, the first interview was arranged and used for the following purposes:

- to obtain baseline data about the research participant and the brain injury survivor (see Table 3.1)
- familiarization of interviewer and interviewee
- to inform participant of procedures and rights
- to give participant the opportunity to ask questions and raise concerns regarding procedures and their participation
- to obtain written informed consent (Appendix C)
- to alert participants to possible emotional responses as a result of participating in the interviews
- to identify a possible support person should this become necessary and indicate formal institutions that provide help, prior to the start of data collection, such as the Brain Injury Group (BIG) in Cape Town¹⁰

¹⁰ BIG can be found under www.heartfoundation.co.za/stroke/strokeSupportGroups.xls

- to commence a personal account of the mothers' experiences being a caregiver to an adult brain injury survivor.

Each participant was interviewed until data saturation was reached, but not more than twice. The transcribed and written-up interpreted notes from the first interview informed and guided a possible second interview to explore the mother's personal story in greater depth. Two interviews were conducted with participants 1 and 2 only. With participants 3 and 4 only one interview was required to achieve data saturation. Member checking was done once all data was obtained from each participant, once all data was captured, and before the analysis process was completed.

3.12 Data management

The data obtained was audio-recorded and then transcribed verbatim. Once the data was collected, the material (electronic copies of recordings, field notes, and informed consent forms) was organized in a readily accessible manner (Seidman, 1998:95). All participants' consent forms were copied and filed in a safe place. All audio recordings as well as the transcripts were labelled with codes (to ensure confidentiality) and stored in three different places (computer, external hard drive, USB stick). Printed versions of the transcripts were kept in an accurately marked folder.

The researcher took field notes after each interview and noted in a reflective journal how her increasing insight into the mothers' perceptions may have affected the procedures she followed and her thinking in subsequent follow-up interviews. These mental reviews were kept in order to not contaminate the data gathered.

In the process of transcribing, certain elements of the personal stories surfaced much clearer than during the interviews, as repetitions became more evident and brief comments revealed their importance in writing. The punctuation was done carefully so as to not impose a certain meaning to what the participants said.

3.13 Data analysis and interpretation

Initially, a within-case analysis (Creswell, 2003) was carried out for each case to extract the individual experiences unique to each participant (Ayres and others, 2003:871-872). Ayres and others (2003:872) advise that 'information must first have explanatory force in one case' before the experiences common to all four participants can be understood.

Each participant's story about the caregiving occupation and her perceptions of herself as occupational being engaging in the caregiving role was analysed by decontextualizing the data and separating it into units of meaning through coding. The researcher marked interesting passages in the text by underlining them in different colours that were assigned to meaning units in the process. An index was kept on the side as a reference for the researcher during the process in which different meaning units surfaced. The data was then recontextualized and reintegrated by combining meaning units of related meaning into clusters that then formed categories. The categories that emerged gave insight into possible themes that apply to each case individually; they also aided the researcher in answering the two research objectives, namely the perceptions of maternal caregivers regarding their caregiving role as well as how the occupation of caregiving is perceived.

This process of coding, sorting and identification of categories and themes is subjective, and the researcher acknowledges that she was 'exercising judgment about what is significant in the transcript' (Seidman, 1998:100). All the transcripts were read and re-read in order to extract all passages of interest. This process of coding was done through three iterations. The researcher decided against the use of a qualitative research computer programme as coding work done on paper enabled significant differences to surface more clearly than when accessed on a computer screen (Seidman, 1998: 108). Seidman suggests that the interpretive response is different too.

Coding/classifying work in the within-case analysis involved cutting out the coded passages according to the colour assigned to each code and group them by placing them on different sheets of paper, according to colour. Before cutting out the coded sections, each transcript was assigned a roman number for the participant in first position. An Arabic number followed, indicating if the data was obtained in the first or the second interview, and in third position the page number of the transcript was noted. This numbering system

was helpful at a later stage in the analysis process when accuracy of information was checked and the extracts placed into context, or to source additional information (Seidman, 1998:108).

For the process of assigning categories, two sets of copies of all transcripts were made, cutting up one copy for the coding process and keeping the other copy intact as a reference. The process of assigning categories was repeated twice to ensure that codes were not locked into categories too early on in the analysis process. Sub-categories emerged from this process that informed each category and 'the recurrence of an idea in different contexts [was] an indicator for a possible theme' (Ayres and others, 2003:872). Insights that derived from one mothers' account caused sensibility in the researcher to similar information in other mothers' accounts (Ayres and others, 2003:872).

The above described process of within-case analysis resulted in a reduced data set that informed the cross-case analysis. For the cross-case analysis the researcher examined all the themes that surfaced in each of the four participants' cases and extracted commonalities of the issues that surfaced (Creswell, 2007). These issues informed the diagram (Figure 5.1) that was developed by the researcher as part of the cross-case analysis. The diagram is discussed in Chapter five and explains a process of transition between caregiver strain and constructive control of caregiving that was found immanent within each case and across all cases.

Through the process of analysing and interpreting the data the researcher learned about new aspects of caregiving. A reflective journal aided the researcher in comparing assumptions with the data that emerged through the interviews. The expectation was to discover consistency between the findings and the literature (see chapter 2). Throughout the process of analysing and interpreting, comparisons of the four study participant's perspectives on the respective topics were possible.

3.14 Quality control and verification

Trustworthiness and rigour were ensured through member checking (Seidman, 1998:100) and by providing an audit trail (Rule & John, 2011:108). The principles of credibility, transferability, dependability and confirmability were applied (Martins, 2008:424; Rule & John, 2011:107), and a theoretical triangulation was done using existing literature to substantiate the categories and themes that emerged from the interviews.

3.14.1 Trustworthiness

To ensure trustworthiness, rigour has to be ensured throughout the entire research process. Pope and Mays (1999:110) suggest that the researcher 'create[s] an account of method and data which can stand independently so that another trained researcher could analyse the same data in the same way and come to essentially the same conclusions'.

3.14.2 Member checking

Member checking means that 'the interviewer – researcher can [later] check with the participants to see if what she has marked as being of interest and import seems that way to the participants' (Seidman, 1998:100). This was done once all themes, categories and codes had been established. Participants were visited with a printout of the interview transcript as well as a list of the themes and categories. The participants were given the chance to verify if what was written about them was accurate (Rule & John, 2011:108) and if it echoed their experiences and journeys adequately. Approval of the pseudonyms chosen for the participants and the brain injury survivors was obtained. The entire transcript was read together, and approximately one hour was taken with each participant to allow for sufficient time to read through the transcripts, and for them to ask questions and raise concerns. They were given the right to rectify or remove data if they disagreed with the content. Access to the audio recordings, transcripts, codes and units extracted was offered but no mother chose to explore this option.

3.14.3 Credibility

To ensure credibility, the researcher applied the principle of reflexivity. Self-reflexivity acknowledges the crucial role of the researcher as subject in constructing the case and conducting the study, and as a major instrument in the study (Rule & John, 2011:35). The knowledge generated is a construction that 'originates in the various choices and decisions researchers undertake during the process of researching' (Mruck & Breuer, 2003:3). Immediate reflection after each interview kept the researcher's feelings and experiences separate from those of the participants to ensure that the findings were a true reflection of the maternal caregivers' experiences.

Ortlipp (2008:695) proposes that 'rather than attempting to control researcher values through method or by bracketing assumptions, the aim is to consciously acknowledge those values'. Apart from working in the field of research, the researcher is a woman and a mother herself which all together indicates that she is not a neutral part in the research process (see Appendix I). Credibility was also enhanced by taking the list of assumptions documented at the beginning of the study (see Section 1.9) into consideration during the data analysis. Assumptions of the researcher were bracketed to ensure that she remains alert to allow the data, rather than clinical experience, to speak.

3.14.4 Transferability

Transferability in qualitative research cannot be understood as an attempt to generalize (Rule & John, 2011:105). Rather, transferability was applied by demonstrating the applicability of the research findings to a larger population. The multi-case study generated a picture of commonalities between four individual case studies: 'by providing thick descriptions of [each] case and its context, the researcher allows her findings and conclusion to gain a level of transferability' (Rule & John, 2011:105).

3.14.5 Dependability

Dependability was defined as the 'attempt by the researcher to account for multiple and changing conditions' as stated by Martins (2008:424). The researcher kept a decision trail of the data collected, methods used and decisions made (see Appendix H for the audit trail).

3.14.6 Confirmability

As emphasized by Shenton (2004:72), 'steps must be taken to help ensure as far as possible that the work's findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher'. Through triangulation it was attempted to make the findings comparable to existing literature across the professional fields. Furthermore, the researcher admitted her own predispositions. Beliefs underlying the decisions taken and weaknesses in techniques underpinning the decisions were acknowledged and admitted. (Shenton, 2004:72). The researcher attended to the aspect of confirmability in Chapter 6.2 (Limitations of the study) as well by providing a short biography (Appendix I) to give insight into the researcher's background and motivation for this study.

3.15 Ethical considerations

The ethical principles of medical research involving human subjects as spelt out in the World Medical Association's Declaration of Helsinki (2008:2) were adopted as an ethical guideline for this study. The four principles that health researchers should use to guide their conduct mentioned by Iphofen (2005:18-19) were adhered to as follows:

3.15.1 Respect for autonomy

The researcher informed participants that

- data obtained would be used for a Master's thesis at the University of Cape Town
- all material would be handled with strict confidentiality (names of people and places were replaced by pseudonyms in Table 3.1 and by numbers in the coding)
- data captured was kept separate from material that could identify study participants; data obtained was marked with numbers instead of participant's names to ensure privacy; the numbered material was kept at the researcher's home, away from any other data that could reveal the identity of participants
- written informed consent to participate in the study as well as for a possible academic publication was obtained
- respect of the mothers' opinions and experiences was ensured; no attempts were made to change their opinions.

3.15.2 Beneficence

- The mothers were given the right to know the findings of the study and to benefit from these (World Medical Association 2008:2), even though direct benefit may be little. A copy of the research report will be made available to participants on request after examination corrections have been completed.
- Although the researcher did not provide advice or therapy to participants and families as a result of making contact, sharing of experiences of caregiving with the researcher may have given a sense of comfort and relief and encouraged self-reflection as well as exploration of the need to ask for assistance or help. Each participant was left with contact details of support services. It is unclear whether any of the four participants have accessed assistance since the research was terminated.

3.15.3 Non-maleficence

- Ethical clearance was obtained from the Faculty of Health Sciences Human Research Ethics Committee UCT (HREC REF: 107/2012, Appendix A).
- Participation was voluntary with the right to withdraw at any time without giving a reason. None of the participants elected to withdraw.
- No remuneration was paid except for travel expenses (if arranged prior to interview).
- The researcher's appreciation was shown at the end of data collection period through informal gifts (sweets and coffee/tea to the value of approximately ZAR 100,-).
- Respect of the mothers' private space and personal experiences (to avoid harm) was ensured.
- The risk of the study was for the mothers to experience an adverse emotional response. Emotional support was provided through pre-emptive referral to appropriate professionals, i.e. counsellors or psychologists. None of the participants requested referral..

3.15.4 Justice

Justice in qualitative research is defined by Holloway as 'distributing benefits and risks fairly' (2005:19). This is understood by the researcher as relevant for this study with regards to making the findings available to occupational therapists and other rehabilitation and health care professionals and therefore expanding service access for this population of second-order patients.

3.16 Summary

This chapter has given an overview of the research process. The methodology used for conducting within-case studies of four individual cases within a cross-case analysis was described, and the processes of interviews and data analysis were described. Ethical considerations were presented. A diagram (Figure 5.1) was developed to show the process that was followed within each case and across all cases.

CHAPTER 4: FINDINGS

4.1 Introduction

A short description of each participant is given with the purpose of providing the reader with a better understanding of their personal circumstances and their socio-environmental contexts. All participants as well as the care recipients and other relevant family members have been given pseudonyms by the researcher in order to ensure confidentiality. The background on each participant is followed by a resumé of the findings, first in tabular and then in descriptive form.

4.2 Introduction to the participants

4.2.1 Participant One: Babalwa

Babalwa is 59 years old and divorced. She lives in a small house in Gugulethu, a peri-urban environment in Cape Town, which accommodates herself, five other adults and one child. She shares her household with her sister, her sister's son, her brother's son, a cousin and her 32-year-old daughter Nobanzi (care recipient), and her daughter's four year old son. She is the mother of another adult daughter and a son who live nearby. Another son was shot and killed 10 years ago. She reports that this event caused a depression that lasted until her daughter Nobanzi sustained the CVA and she, Babalwa, came to realize that her daughter needs her and that she needed to be there for her.

She reports that her main source of support is the cousin who lives in her household. The cousin helps with care and support for Nobanzi. Babalwa lives on an income of R2200,- per month. R1200,- is derived from her pension, and she generates an additional R1000,- from her Spaza shop, selling airtime and other basic necessities¹¹. She says that her own health is not very good due to arthritis in her knees and hips. She is overweight, and it was observed during the research meetings that she has difficulty walking. She requires a stick to keep herself upright when walking. Babalwa's occupational profile consists of spending some hours of the day in her shop that she runs from her home. The larger portion of the day though is spent either with Nobanzi or resting. Nobanzi still requires help with washing

¹¹ Nobanzi has not been eligible for a disability grant until now as it is unclear if she may return to work. Her employer has kept her position open for her until now.

and dressing herself as well as with facilitating a daily routine. Babalwa ensures that Nobanzi has her medication on time and that she takes her meals. Furthermore she ensures that Nobanzi does not spend all day in her room listening to music, watching TV or sleeping but engages in a more active and participative lifestyle within her family. Babalwa has recently started going to church again which she used to enjoy prior to her son being killed 10 years ago. She used to go out with friends some times until late at night but has not yet engaged in any of these leisure and social activities since Nobanzi's ABI.

Her daughter Nobanzi had a cerebrovascular accident (brain aneurysm) 11 months ago, and since then Babalwa has been the primary caregiver. Her daughter's aneurysm made her aware that she has not lost another child but that her daughter is still alive and needs her. This gave Babalwa the motivation and inner power to walk again and improve her relationships with her other children. She describes herself as someone who used to be 'on the outside' but now she is 'on the inside' because her daughter Nobanzi gave her back her life and her smile (i.e. a reason to live).

4.2.2 Participant Two: Erika

Erika is 65 years old and lives in a small double-storey house in Athlone, an urban environment within the city of Cape Town. The home houses five adults and three children. She lives downstairs with her husband and their son Shawn of 40 years old (care recipient). Upstairs live her daughter and her husband with their two sons and one daughter. Erika is a mother to another two adult sons who do not live with the rest of the family but stay close by.

Erika reports that she has physical and emotional support from her daughter and son-in-law. One of her sons regularly asks about Shawn's wellbeing but is not actively involved in any way. The family lives on her pension of R1200,- per month as well as an additional R350,- from a social grant. The money from the Road Accident Fund claim may come through in the near future but had not yet at the time of the interviews. Major changes to their living circumstances are anticipated in connection with the long-awaited payment.

Erika reports that her occupational profile consists mainly of her caregiving duties and that she has very little time for herself. She does all her own housework and reported being very neat. She used to be part of the church choir and attend church regularly once to

twice a week, but since her son's brain injury she stopped because she felt she could not leave him with his father only. Furthermore, she reported often being too tired to engage in any activities other than housework and providing care to her son Shawn. Up until the time of the interview she had not resumed her recreational activities.

Her son Shawn sustained a traumatic brain injury four years ago. He was involved in a motor vehicle accident as a passenger in the vehicle. He was in hospital and received in-house rehabilitation for three months. Since his discharge she has been the primary caregiver. Erika describes herself as a 'natural caregiver'. She says being a caregiver is hard but that for her it is easy because 'she has the passion of being a mother'.

4.2.3 Participant Three: Sarah

Sarah is 75 years old and lives with her husband (80) and her son Robert, 52 years old (care recipient) in a house in Camps Bay, an affluent area of the Cape Town metropole. The house is spacious. She has two daughters who both live overseas. Sarah goes to see her younger daughter and her two children in Switzerland once per year. Her other daughter lives in Australia, and they do not see each other as often. Sarah expressed in the interview that she would never have chosen to become a caregiver and that she feels strain. She said that she would possibly have considered the option of sending Robert to a home (a residential care facility), but her husband would not have approved. If she had insisted, Sarah believes it could have ruined their marital relationship. Her husband is very dedicated and actively involved in Robert's care on a daily basis.

Sarah, her husband and Robert live in Robert's own home that he purchased before the accident. The income that Sarah, her husband and Robert live on is the husband's private pension of R10.000,- per month.

Her son Robert sustained a traumatic brain injury 17 years ago. He was hit by a car as a pedestrian. Erika and her husband have been primary caregivers since the onset of his brain injury. She says that believing in God helps her through her hardship.

Her occupational profile consists mainly of caregiving duties and housework. She occasionally meets with a friend for coffee or a walk, and she goes to church once per week.

4.2.4 Participant Four: Soliswa

Soliswa is 42 and lives with her husband and her adult daughter and two sons, of which the 19 year old Thandiwe is the care recipient. Her daughter has one child of six years old who also lives in the household. The family lives in a house that has a permanent structure in Phillipi East, an informal suburb of Cape Town.

Between her and her husband there is no income at the moment, but they are still receiving a short-term disability grant for Thandiwe until the end of 2012 that amounts to ZAR 1170,- per month. Their other two children can offer no financial support to the household as they still go to school. Thandiwe has never worked as he was still a student at the time of injury.

Thandiwe sustained a cerebrovascular accident eighteen months ago. He had a brain aneurysm. Soliswa says that looking after Thandiwe makes her happy. To show him that she cares about him and that she loves him it is not difficult. Her occupational profile is characterized mainly by being a caregiver to Thandiwe.

4.3 Findings

Table 4.1 depicts the findings in tabular form. It shows the one theme that emerged: maternal caregiving in the context of ABI entails 'Being the Holding Environment'. The theme was substantiated by two categories namely, 'Maternal Caregivers as Containers' and 'Maternal Caregivers as Conductors'. Each category was informed by two sub-categories. The category of 'Maternal Caregivers as containers' consisted of 'Accepting States' and 'Non-Accepting States'. The category of 'Maternal Caregivers as Conductors' consisted of 'Knowing How To' and 'Not Knowing How To'.

Table 4.1: Findings

THEME	CATEGORIES	SUB-CATEGORIES
'Being the Holding Environment'	Maternal Caregivers as Containers	Accepting States
		Ambivalent States
	Maternal Caregivers as Conductors	Knowing 'how to'
		Not knowing 'how to'

4.3.1 Theme: being the holding environment

The maternal caregiver creates a holding environment within which the care recipient recovers and functions. The theme suggests a merging between the mother's life and that of her care-dependent adult child. The mother holds both her own and the care recipient's 'being' and 'doing' in dynamic tension. The theme overarched two categories which were each informed by two subcategories. Maternal caregivers of ABI survivors act as containers of the emotional needs of the ABI survivors as well as conductors of caregiving tasks, i.e. holding tasks such as washing, dressing, feeding the care recipient amongst other tasks. Participants described their perceptions of the caregiving role and occupation of caregiving as oscillating between acceptance and ambivalence towards the impact the occupation of caregiving has had on them. Faced with the complexity of ABI caregiving, mothers also oscillate between 'knowing how to' (being capable) and 'not knowing how to' (feeling incapable) provide care. The dynamics between the two categories is presented and substantiated by pertinent, descriptive portions of the narratives of the research participants.

4.3.2 Category One: maternal caregivers as containers

This category speaks on the 'being' component of the caregiving role and contains two sub-categories, namely 'Accepting States' and 'Ambivalent States'. Narratives providing insight into the maternal caregivers' emotions that reflected their commitment informed the subcategory of 'Accepting States'. It illustrated the acceptance of the impact that the ABI had on the mothers' lives and their acceptance of the caregiving role. The 'Ambivalent States' were characterized by feelings of worry, doubt and resentment and showed a state of being in two minds about the caregiving role at times.

The caregiving role is marked by a constant transitory shift between acceptance and ambivalence. It is shaped by the maternal caregivers' reflections on their feelings (internal factors) as well as by set-backs such as financial or health problems arising and possibly other external factors.

Subcategory One: accepting states

The accepting states encompass affirmation of the role of being a maternal caregiver. Different emotional states experienced by the four participants are presented and substantiated with narratives below.

Above all, the merging between the mother's state of being and the ABI survivors' state of being stood out in all narratives extracted from the data. This characterized the role of the mother being a container of her own and the care recipient's emotions and holding it together within herself. This aspect featured strongly in the data. In order to avoid Shawn getting irritable and stressed, Erika ensures that she prepares everything for him in the morning so that he can do whatever he likes, before she gets to do anything else. Erika explained:

First thing I settle him in the morning. Have his breakfast, see to him, room is clean, everything is clean. Then I know he can do anything he wants to do. When he is relaxed, I am also relaxed. If he is not relaxed, I am not relaxed.

Similar to Erika, Soliswa reported:

When he is getting better, I am also getting better. When I see my son is recovering, I am also recovering.

The state of being **understanding** was equally extensively expressed by most of the participants. Understanding incorporates awareness of the role demands of being a caregiver. It consists of the realization of and reflection on the joys as well as the hardships that form part of the caregiving role. It also incorporates awareness of the impact that the injury had on the survivor's life. Changes that have occurred in the family's life are not necessarily considered to be bad. They are referred to as both burden and benefits. Babalwa gave an account of how the mother-daughter-relationship changed to the better since Nobanzi's ABI. In other words, Babalwa's relationship with her daughter benefited from the occurrence of the ABI. It helped Babalwa to gain a new understanding of her role as a mother:

The relationship with Nobanzi was not so good in the [first] time when she did not have the accident. We fight a lot 'cause she [go] went out a lot with her friends. But now my relationship with Nobanzi is daughter and mom. Nobanzi did not give me a lot of time to talk sometimes. But now I can see I am a mom. The change happened while Nobanzi was in hospital. I was the only one visiting her. I have re-connected with all my children. I am a very strict mom but now my children can talk to me. They come to me now. Very positive change. Nobanzi gave us a very positive change.

The need for support featured in all mothers' accounts. Regarding support from family and friends, Erika highly values the efforts of her son-in-law. He appears to be a reliable source of support with good skills and a lot of patience. She reported:

He sometimes has more patience with Shawn [than she herself]. When there was a time we had to take Shawn to the toilet, he did not moan. He did it for him. Now, the other day he took Shawn for a walk to fetch Brenda from the crèche with his walker. It was about a five minute walk but Shawn takes longer. It was a windy day. He has patience with him.

Other than his support, Erika has no other physical support as her husband does not actively involve himself with their son. She finds great support and strength in her church though.

Equally, Sarah also experienced a lack of support from friends and family (except her very supportive husband) but finds a reliable source of support in her faith and her church. All the participants commented on the value of having faith that contributes to their ability to carry out the caregiving role day by day; that provided a much-valued support. Their faith consisted of a belief and trust in God as well as a belief that their children were going to get better, which gave them **hope**. This optimism helped them to emotionally handle the role demands of being a caregiver and was expressed by Sarah in the following way:

You gotta believe. You believe in God, that is the main thing. You get a lot of strength ... that helps a lot ... and the church too. They are very good. I am a Christian ... it is very good If you can find the Lord it helps a lot. It is a personal feeling that you feel, not religious. It is becoming a Christian. Accepting Jesus as your saviour. You know, you still have your up and downs ... you don't have to kneel down ... you talk to him all the time. That's what you do.

All mothers voiced their commitment and dedication to their sons and daughter who sustained ABIs. They expressed the different ways of their involvement in their childrens' lives in order to make their lives easier. The extent of dedication Babalwa showed highlighted the **resilience** that she has, being a mother and caregiver. She shared her memories from when she received the doctor's phone call when Nobanzi sustained the ABI and went to the hospital to go and see her:

When Nobanzi was in hospital, I started walking again. I am the only one, I am her mom. The doc phoned: 'You can come'. When I get to the hospital there is a wheelchair. I said 'no, I want to walk with my stick. I want to feel Nobanzi; feel her pain, feel her again'. And I did feel her. Gave me power to walk.

The narratives presented above show the emotional impact of the caregiving role on the mothers. The ABI survivors' wellbeing is interlinked with their own well-being and understanding, and their belief guides the mothers through the role demands and hardships of being caregivers to ABI survivors.

Subcategory Two: ambivalent states

The ambivalent states encompassed oscillation between acceptance, lack of acceptance and disavowal of the role of being a maternal caregiver. The mothers expressed feelings related to worry, loss and resentment. Despite all of them being committed and most of them devoted to their caregiving roles, they sometimes found themselves in two minds, acknowledging the hardships that come with being a caregiver to their children who sustained an ABI.

The two major aspects of this category seemed to derive from feelings of worry and loss. The worry comprises feelings such as anxiety, unease and concern. This state shaped all participants' experiences of being maternal caregivers substantially. Concern regarding their children's safety was the most striking aspect of the participants' state of being worried. Soliswa explained:

I always worry because he got fits after the accident. But before the accident there was no fits, the epilepsy. He has got that. I am so worried. Maybe nobody home. He stay[s] alone sometimes ... I am also worried maybe he fall[s] again ... and it can happen again ... I don't know.

Mothers felt ambivalent about the quality of care that others besides themselves could provide. They believed that only the mother could care well enough or sufficiently for the ABI survivor. Any other person would most likely not care enough or in the right way. Erika expressed her feelings toward her son wanting to live on his own and her concerns in this regard.

He wants to be on his own but he can't. He thinks he can be on his own but he really is not at the stage where he can be on his own, 'cause I can see that. He can't. He needs help. He was ... he is ... he was a very independent person. He wants to be on his own but he can't stay on his own because the girlfriend left him, so there is nobody that is going to care for him. We can't trust anyone to care for him. So I say to him he must stay as long as he can until the day that he knows he can stay on his own. If he had someone caring like I care for him, then I would let him go. But he must find the right person.

Another aspect that illustrated ambivalence in the mothers' feelings was the perceived lack of understanding by other family members that mothers experience and which is a reason

for their worry. Family members do not adjust their behaviour towards the brain injury survivor to the extent the mother feels is necessary. Soliswa felt that her children should be more understanding and considerate of Thandiwe as an ABI survivor and his needs:

Sometimes the other brother and the sister, sometimes they don't understand it. And when I explain to them sometimes when they have a talking or a little fight, when I try to, suppose to stop them even when he is wrong because I am worried they don't understand the situation of him. When he is cross you are not supposed to argue with him. Let him go. Told them not to argue with him ... but my other kids they don't think about that when they are fighting. They don't think that he has a brain injury. They don't think about him.

Like Soliswa, Sarah shared her feelings about the lack of understanding and consideration of friends and family and the lack of support. She spoke about her sister-in-law's reaction when helping with her son Robert on a once-off occasion:

I suppose I could say I learned who my friends were ... what my family is like sometimes ... I mean, my sister- in-law watched, looked after him once with her husband ... it was just one night ... and the next morning they could not get home quick enough. You know ... they were really going ... you learn a few things.

Lack of understanding and loss lie closely together, and the aspect of loss requires further investigation. Loss encompasses different qualities, and a feeling of loss of some kind featured in all the mothers' accounts. There were different facets of loss, with having lost the son or daughter they used to know coming out most strongly. Missing the child that the ABI survivor used to be was expressed by Sarah as follows:

I think in the beginning you do get depressed. You know, it will depress you. Because you think about how Robert was. He was a very good-looking, athletic type. Always out on the sea and everything and now his life has changed right over to sitting in a wheelchair.

In alignment with Sarah's account, Babalwa shared:

When I look at Nobanzi, she is not the same child as she was before and that hurts me very much. Sometimes when she talks to us it is like a little girl of six or five years old and that hurts me very much.

Another aspect of loss that surfaced was the loss of personal freedom and time. Erika shared her experience of the time-consuming nature of being a caregiver related to a lack in drive to engage in activities that may be interesting and health promoting for the mother. Despite her dedication and love enabling her and keeping her going, she reported exhaustion when she gets to the end of the day. She spoke about having passion for being a caregiver and that her passion is making it easier for her to endure the hardships of being a caregiver, but also realizing the extent of the role demands of being a caregiver:

There is hardly time for myself. After caring for Shawn it's my own work that I have to do. If I get a rest during the day it is about for an hour, for the whole day before I go to bed at night. After the day ends with Shawn and myself, then I am very tired and I don't feel for anything. I just want to go to bed.

The loss of personal freedom came out clearly in the interview with Soliswa. Even though she states that her commitment and love for her son outweigh the feelings of loss, she reported feelings of having lost her freedom because she worries all the time:

Before, you know, I was free. Because at home there is no ... all my children are fine. But after the accident ... [...] when I am not home I was worried since the accident. I am not free. But, I lost that freedom and I don't care. You see, I lost it but I am with him ... I feel happy because I said then, when he was in the ICU, I said 'God, give him a chance. I don't want him to die. I don't care how he is, if he can't walk or something happen[s] to him. I want him back. I will look after him with all my heart'. I am happy, Inge, to look after him. It makes me happy. Because, to show him I do care about him and I love him. It is not difficult.

Soliswas' narrative shows awareness of the loss but at the same time is free from feelings of resentment or regret. In contrast, the latter were reported with emphasis by Sarah who expressed her feelings of loss in the form of personal shortcomings as a result of her son's ABI. She expressed how the ABI impacted on her life and her relationship with her

husband. She expressed a lack of active involvement in decision-making regarding Robert and their own lives and how she would have preferred Robert to be in a nursing home many years ago but that her husband would never have approved.

Sarah voiced that her feelings of **resentment** are sometimes joined by feelings of frustration and annoyance towards the role demands of the caregiving occupation. She said:

Sometimes you get angry and then you say 'behave yourself' and you really want to ... I can understand why some people ... you know the caregivers at the homes, they want to throttle them ... those old people they look after... but as I say ... it could have been a lot worse... and then... and D (the husband) wanted him home. No, he did not want to put him into a home... [...] Maybe I would have liked to put him away but Douglas¹² [the husband] would have never liked ...

To provide care to an ABI survivor can be very challenging, and the required caregiving abilities to be equipped for its challenges are not automatically obtained. They also do not come easily and may not be what the caregiver anticipated as a desirable occupation for her own life. The lack of understanding and support from other family members together with the mothers being in a state of worry and feeling of loss shows the extensive demands on the caregiving role. The mothers are the ones who are containing all these emotions as well as the emotions of their children who sustained ABI; this illustrates that the needs of second-order patients should be considered by occupational therapists.

¹² Pseudonym

4.3.3 Category Two: maternal caregivers as conductors

This category speaks to the 'doing' components of performing caregiving as occupation. The mothers act as conductors of caregiving tasks that are also referred to as holding tasks. The nature of tasks varies, depending on the needs of the ABI survivor. It incorporates feeding, dressing and washing the ABI survivor, as well as talking and praying. The data analysis revealed that each maternal caregiver has a highly individual approach to caregiving as an occupation and that the perception of the role as maternal caregiver is a process of adjustment that oscillates between acceptance and ambivalence. Mothers oscillate between 'knowing how to' and 'not knowing how to' provide care. This impacts on the maternal caregivers' perception of being capable or incapable and gives insight into how mothers of ABI survivors could be addressed as second-order patients in the occupational therapy service provision.

The resilience which the mothers reported was inconsistent with the existing literature. Paucity of research on the extraordinary persistence and spiritual, physical and mental strength of the maternal caregivers of ABI survivors was confirmed.

Subcategory One: knowing how to

This sub-category speaks on the capabilities and competencies of the mothers performing the occupation of caregiving. The significant caregiving tasks that emerged from the data are presented below.

Engaging in the occupation of caregiving is marked by different ways that the mothers actively involve themselves in the everyday life of the ABI survivors. The demands that are placed on the maternal caregivers differ according to the needs of the ABI survivors. Erika gives a picture of a typical morning in her life, providing assistance to her son Shawn:

Every day I get up at half five, get myself ready for the day, take my breakfast early, take my tablets so that I don't get sick. That is the most important thing. Then, if I still got the time, past seven, I take Brenda¹³ to the crèche. Come back to see to Shawn. See that he goes to the bathroom, brush teeth, whatever he has to do in the bathroom. Then I make up his bed and clean the room for him and then I prepare his breakfast. Then he will have his breakfast and I can start my other duties for the day.

Caregiving tasks are not necessarily related to the execution of activities of daily living but can also consist of activities such as sitting and talking, as was presented by Babalwa. She stated that the biggest help that she is able to give to her daughter Nobanzi is to sit with her and her other children. This is an occupation that she did not use to engage in prior to Nobanzi's ABI. She perceives this change as very beneficial to everyone and explains:

I love my children but I am not a mother to sit with my children and talk with them but now I do that. I have changed a lot. Now I can call them and sit with them and I talk to them about everything that happens in my life, in Soleka's¹⁴ life, in Nobanzi's life. We come together and talk.

To be able to care patiently requires the ability to endure demands that can be challenging and that arise from performing the practical activities and tasks associated with providing

¹³ Pseudonym

¹⁴ Pseudonym

care. The occupation of caregiving incorporates a multitude of highly demanding tasks performed for a person who may not be rational, may be impulsive and may lack empathy for the caregiver. Erika describes a scenario that explains her performing a caregiving task that requires a lot of her patience:

He can be aggressive because of the accident or he ... how can I say... or he can be emotional but I can handle it. Sometimes I do give him an answer. If he gets too aggressive I speak to him in a nice way just to calm him down and that helps. And sometimes I keep quiet, let him speak his heart out or whatever, then later he will say sorry mom that I hurt you that way or I said the wrong thing. And I say, it's ok.

Erika described as one of her caregiving occupations having to act as a mediator between Shawn and her husband. They frequently get into arguments over the television program, and then Erika has to stop them fighting. She says:

It is only him and his dad. That is the only part when he ... that's when he gets aggressive ... and then I have to come in. Then I just stop the two of them 'you just stop your arguing. Find another solution to calm you down!'

Performing the caregiving role responsibly requires sensibility and dependability. Attending to the needs of the ABI survivor requires the mothers to attend to their own health as well in order to be able to carry out their role demands of being caregivers. Erika explained how she takes responsibility for her own health in order to be able to look after her son Shawn's needs. She is aware that her son's wellbeing depends to a certain extent on her own health for her to be able to provide him with the care he requires. She reports:

I do have to take care of myself to take care of him. I am more aware because of when I got sick in 2008. Now I need to take care of myself also.

Another way of providing care was expressed by Babalwa who spoke about spiritual support of her daughter. This caregiving task aimed at uplifting contains assurance that there is a God who provides and who inspires people's doing. In the interviews with Babalwa, she stated repeatedly how her belief makes her strong and how she is trying to encourage her daughter Nobanzi to believe in God and herself as well to gain strength, through sitting with her and talking.

I sit down with Nobanzi and talk to Nobanzi and I said 'you see, God gave you another second life. You must be proud of yourself and you must be proud of God'. [...] 'You must be proud of God. I'm proud of god and myself'.

Subcategory Two: not knowing how to

This sub-category speaks on the inability to provide care, i.e. performing certain tasks that are physically or emotionally challenging. It can lead to the point where the caregiver feels unable to do it. These aspects will be explained and substantiated with narratives of the participants in the following.

Lacking the ability to help the ABI survivor sufficiently with his activities of daily living surfaced in the interviews in different ways. The reason for not being able to help their sons or daughters more effectively was mentioned mainly as a physical limitation, but doubt regarding their emotional abilities was voiced as well. Babalwa expressed her physical limitations and concerns related to it:

Because of my knees and my back pain, then I can't stand long to give her some help sometimes ... It is difficult sometimes because she must be washed and she must be dressed and sometimes I can't do it. Then I must ask my cousin's brother to do it or my cousin's sister to do it and then I become depress[ed] all the time.

When Babalwa was asked how she copes with the frustration of her daughter sometimes talking *'like a little child of six to five years old'* she said that she gets harsh with her. For lack of knowing how to get out of the situation, she reported that

'sometimes I am very harsh with her. And then she goes to her room and I stay in my room'.

In moments of frustration, when Shawn gets upset or aggressive, Erika shared that she removes herself from the situation because she does not know how to deal with his behaviour :

I do understand that I think it is part of his mind triggering it but I just walk out. I just walk out and I come and sit and relax. I just sit and relax, that is all. And the thing goes away.

Soliswa described her way of dealing with her feelings of not knowing how to deal with the situation of her son's brain injury as follows:

Sometimes I don't understand him. I forgot. No, it is not that I forgot but sometimes I want to be hard on him. I don't know but I want him to forget about the accident. Sometimes I am hard.

Sarah expressed a complex dilemma regarding her perceived inability to provide care for her son Shawn. She illustrated her situation of not having chosen to be a caregiver and resenting it. She has withdrawn from her son and performs caregiving occupations mainly out of duty of being his mother and primary caregiver:

We used to take him out for outings. In the beginning ... we used to go twice per week and now we go once per week. You don't know what they are thinking, but he could concentrate and watch it.

Sarah further shared insight into her emotions. She spoke about how she sometimes feels like she just wants to go away. Her inability to cope with the caregiving occupation speaks out of this narrative:

The other day I said I am going out because I had enough of everybody ... and I said I am going to Switzerland today ... I met Janet (good friend) and we went for a walk in the park. We had coffee there. Then I came back ... I wanted to stay away the whole day and I came back at one. I decided not to leave. I think it was important to take time off. You must do that because it drives you dilly all the time.

Sarah furthermore shared that her frustration and feelings of not knowing how to do it, perceived as annoyance and infuriation, have on some occasions become so pronounced that she became physically abusive to her son Robert. When asked how she handles her own anger that she expressed, Sarah replied:

Well, I don't do anything to him ... once I did ... I got so cross I slapped him ... Lord, just excuse me for my behaviour ... human nature is terrible ... you know that?

4.3.4 Interface: transitions between caregivers' strain and constructive control of caregiving

Caregiving entails the role of 'being' the caregiver as well as the actual occupation of caregiving, the 'doing' side of it. Both these aspects inform the caregiving experience and how maternal caregivers perceive their role as caregivers and the occupation of caregiving. Oscillation and transition occur constantly between the different states, between accepting and being ambivalent of the impact the occupation of caregiving has on them, as well as between being capable and feeling incapable to provide care. Ultimately, the 'being' and 'doing' comes together in the holding environment where the maternal caregiver acts as the main source of containment for the ABI survivor. Furthermore, she acts as a conductor, carrying out the caregiving occupation. The statements below have been chosen to show the complexity of caregiving within the transition process between caregiver strain and constructive control of caregiving:

Becoming a caregiver, I can say, it's a hard job but for me it's easy. Because I think I have that passion of being a mother, caring for kids all the years, caring for others and I have the passion. It can be hard but I can try not to get cross. It is sometimes emotional but I can handle it. It is something you can't describe actually but for me it is a real pleasure caring for somebody (Erika).

Another intersection of categories surfaced in the interviews with Erika. This interface shows how oscillation occurs between categories, the being and the doing, and how Erika oscillates between feelings of accepting and ambivalence:

Last week he got to the toilet on his own, he does everything for his own. But then his mind gets full or I don't know what, and he shouted at me that I must clean him; but he is clean. I think it is all in the mind and it just makes me feel a bit ... how can I say ... then I don't feel like, I am feeling, what did I do wrong? Why is it? Then I just ask him, 'why do it happen now?' ... and then I feel a little frustrated. Then I calm myself down. Afterwards he came in with the walker, banging it, 'haven't I got patience for him?'. I say 'I do have patience'. Then he came back standing there ... 'Sorry Ma, sorry, sorry'. I say 'I care for you and I do things for you but you must also care for yourself'. And then he said I look down to him he said and I say 'no, I don't look down'. I just want him to understand, and I take the cloth and I wipe him and I show him

he is clean but I think it is all in his mind. That is only the part that sometimes triggers me.

Sarah's statement echoes the ambivalence of acceptance and disavowal shared above by Erika. Her ambivalence refers to the living arrangements of her and her husband together with her son. She believes it would be better if Robert were in a nursing home but has her concerns:

At one stage we did think of putting Robert away but then the homes were terrible ... it was 12 years ago ... I believe everything is better now ... things... He might have to go ... he will have to go in one day ... he can't forever like this... I take each day as it goes ... [...] We take it day by day and if he has to go in, he will have to go in. In the next two to three years he will have to go in. We have had him all the time. He knows this house. But eventually you have to use your kop (head) a little bit as well as your heart and you realize he will have to go in. But I am sure we will find something. And we can't say how long we are going to live and how long Robert is going to live ... He has never been sick ... if we would given him away that would be different.

External factors can make the caregiving role even more challenging and affect how the occupation of caregiving can be carried out. Health setbacks as experienced by Erika when she sustained a CVA herself in 2010, one year after the injury to her son, can impact on the mothers' ability to attend to the role demands of caregiving physically, emotionally, psychologically and cognitively. Comparing the ABI survivor to others can have a positive effect on the mother, as it had on Sarah:

Sometimes I am angry and other times I think it could have been a lot worse ... when I saw some of the other patients ... he could relax. He could move and then you think oh, he is doing so well and then he goes off again ... and then you think, I am gonna wring his neck ... you feel like it sometimes ... it's funny.

But it can also be depressing. Other ABI survivors may be less impaired or more functional than the own child.

Another external factor that was clearly stated by Erika is financial strain and socio-economic difficulties. Financial strain can affect the ability of the caregiver to perform the caregiving occupation. Erika explained how she was going to make necessary changes to the house that has very limited space, which may currently contribute to tension between her son and her husband, especially when it comes to the TV situation.

When we get the money (from the Road Accident Fund), we are going to extend the room a little bit so he can have a little part for himself and a TV on his own, not disturbing each other. Shawn sleeps on the sleeper couch and he needs a bigger bed. So if we gonna get the money, we are going to get a bed for him.

4.4 Summary

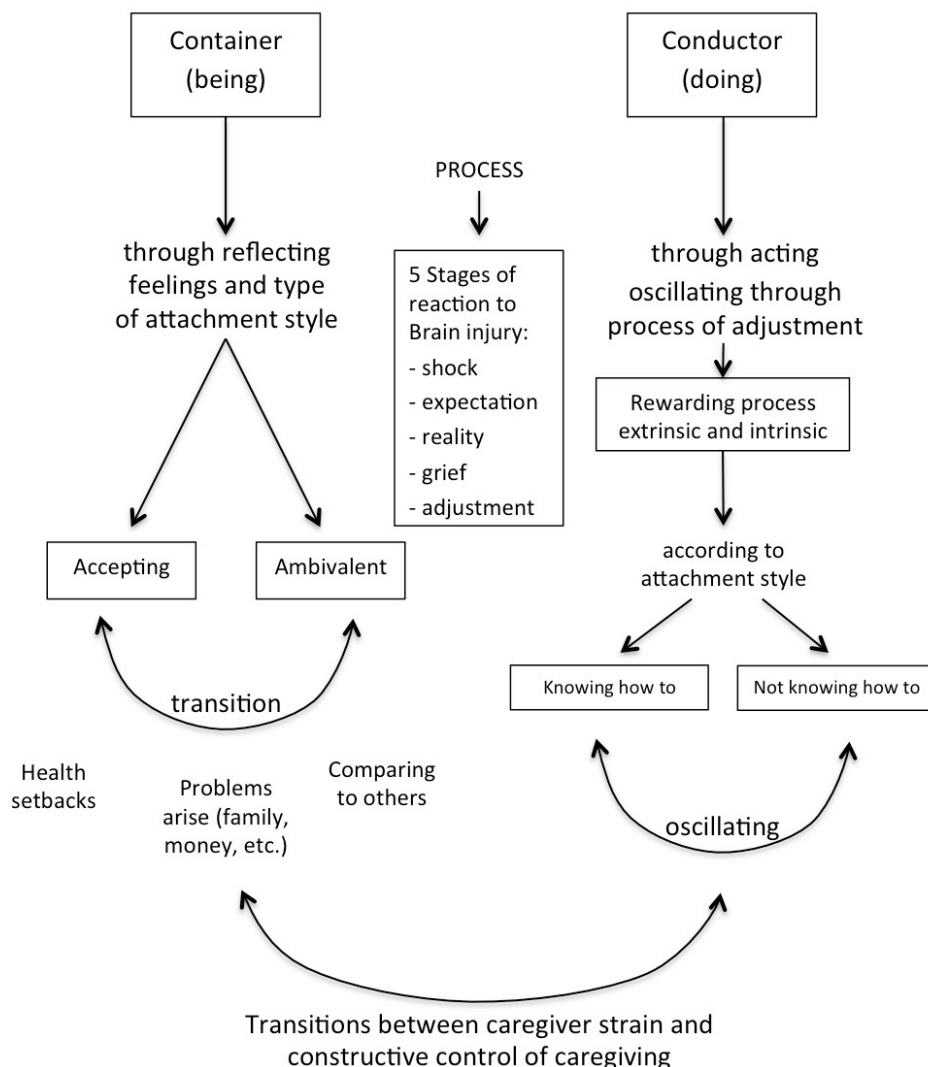
This chapter presented the findings of the within-case and cross-case analysis in the form of one theme, two categories and two sub-categories each. They were illustrated in a tabular format (Table 4.1), elaborated on in writing and substantiated with narratives of the research participants. The perceptions of the participants regarding their caregiving role and occupation of caregiving varied, as each mother has a highly individual experience of her role of being a caregiver as well as performing the occupation of caregiving. Many of the feelings that emerged from the data were shared by different mothers. However, how they carried out the occupation of caregiving differed from mother to mother. All mothers gave account of the oscillating nature of caregiving, as it transits from being accepting to ambivalent as well as shifting between knowing how to and not knowing how to. This process is called the transition of caregiver strain and constructive control of caregiving. Three of the four mothers expressed more benefit of providing care to the ABI survivors than burden. The fourth mother expressed clearly how she would never have chosen to become a caregiver and that she would have preferred her son to be in a care facility.

CHAPTER 5: DISCUSSION

5.1 Introduction

In this chapter the dynamics of the findings are discussed, using an illustration that depicts the processes involved with maternal caregiving in the context of ABI. The one theme that surfaced from the data analysis, namely 'Being the Holding Environment' was informed by two categories, namely 'maternal caregivers as containers' and 'maternal caregivers as conductors'. Figure 5.1 below illustrates the processes that operate within and between the categories and sub-categories.

Figure 5.1 'Being The Holding Environment' Diagram



The connective thread between the categories is informed by maternal attachment, a bond that mothers have to their children. This informs how they act out their roles of being caregivers and how they perceive their occupation of caregiving. Maternal caregivers are the key roleplayers in creating a holding environment (see Winnicott, 1965:148) within which the ABI survivor functions. They are the ones who typically 'hold' the child, emotionally and physically. They act in a field (the interface) that is informed by transitions between the caregiver's strain and constructive control of caregiving tasks. When being in an accepting state and feeling capable of performing the caregiving occupation it can be considered as being in constructive control and able to act on it. If the ambivalent and disavowal state weighs higher and the mother has the feeling of not being capable of performing the caregiving occupation, she is most likely taking strain. But again, these two processes are oscillating. The interface is shaped by the doing and being that are immanent within every mother. Both are interlinked and inform each other.

A contextualization of the findings within the theoretical framework of attachment theory will be provided. Each of the processes within the two categories will be discussed on their own with the influencing factors that facilitate the transitions between the categories, and the interface between the two processes will be explored and discussed.

5.2 Explanation of figure 5.1

Figure 5.1 illustrates on the one side the process of transition between accepting and non-accepting of the role of the maternal caregiver as container. It shows that depending on their type of attachment style and through reflection of their feelings, they oscillate between acceptance and ambivalence. This means accepting the impact the injury had on the survivors and their own lives as well as on the lives of other family members. Ultimately, the maternal caregivers are accepting or ambivalent towards their caregiving role and its demands. It is not necessarily the entire role that is not accepted, but may be parts of it, and the level of acceptance can differ from day to day or from one aspect of caregiving to another. In answering the study aim, maternal caregivers perceive the caregiving role, enacted through the occupation of giving care, as a constant transition between acceptance and ambivalence as well as feeling capable or incapable of performing the caregiving occupation. This transitional affective state shifts in response to emergent internal factors (the mothers' worries, fears, sadness, loss etc.) and external factors

(monetary problems, comparing the child to others, caregiver's own health, family problems etc.).

On the other hand, Figure 5.1 illustrates the transitional process between being capable and not being capable of the tasks that constitute the caregiving occupation. Through acting as caregivers, mothers experience a rewarding process of 'doing' things for and with the ABI survivor. The reward can be intrinsic (e.g. sense of achievement, joy, caregiving as an action of love) or extrinsic (recognition of hardships by friends, family and society). Simpson and Rholes (2010:174) suggest that the motives behind caregiving differ and are dependent on attachment styles. They explain that people who are secure within their attachments appear to care for reasons of wanting to make the care recipient feel better, whereas people who are characterized by an avoidant attachment style care more about themselves as caregivers. Anxious people seem to care for reasons of creating a stronger connection between themselves and the care recipient. Perceiving themselves as able or unable also depends on the type of attachment people experience. The literature on caregiving indicates that avoidant and anxious people offer care in different ways with regard to both quantity and quality (Sullivan and others, 2011:174). This influences the maternal caregiver's ability to accept and be committed in her caregiving role or, on the other hand, her experiencing ambivalence and disavowal in it which in turn impacts on her perceptions of capability. When incapability was experienced, it was generally the inability to carry out certain caregiving tasks, for example not being physically able to help as much as is needed because of personal physical limitations or not having enough patience. However, 'not knowing how to' can be overcome by carrying out the caregiving tasks and getting feedback from it. By performing caregiving tasks successfully, the maternal caregivers' perception of 'not being able' can be transformed to a feeling of 'being able'. Learning how to 'do' or 'perform' the caregiving occupation and how to cope with its various challenges lies at the core of 'being a holding environment'.

This 'core' is the most obvious access point for occupational therapists to consider maternal caregivers as second-order patients. The challenges and hardships of the caregiving occupation could be approached, discussed, processed and guided by an occupational therapist who, together with the caregiver, can address the executional components of the caregiving or 'holding' tasks in the form of caregiver training. Equally important though is the focus on the emotional side of caregiving and to facilitate

processing in this regard. The theoretical framework of attachment theory can be a helpful resource as it postulates that people can change the ways in which they attach to other people, regardless of what attachment pattern they may previously have had (Meredith, 2009:286). This is where occupational therapists would be able to assist the caregivers with emotional and executional components of caregiving. However, an occupational therapy intervention at any stage in this process would be highly beneficial to assist maternal caregivers in coping with the role demands of and the activities required of a caregiver and navigator within the 'holding environment'.

In between the two processes described above (see Figure 5.1) a process of transition occurs between caregiver burden and constructive control of caregiving which defines the interface of 'being a caregiver' and 'doing caregiving'. It is characterized by the one affecting the other. Being and doing have to be understood as interlinked and mutually influential. They cannot be seen in isolation if the caregiver's needs are to be addressed holistically in the holding environment. Mothers' motivation to provide care is what navigates them as caregivers through the joys and hardships of the 'holding environment'.

5.3 Contextualizing findings within theoretical framework

The theoretical framework of attachment theory (Bowlby, 1988; Bowlby, 2005) was chosen because it provides a language and structure for the phenomena discovered through the inductive data generation. The data that surfaced spoke clearly of the concepts of attachment theory which made it a highly suitable framework to use, being 'the best supported theory of socio-emotional development yet available' (Bowlby, 1988:28). It describes the dynamics of long-term relationships between humans and has its origin in the work of psychiatrist and psycholanalyst John Bowlby who, after the second world war, engaged in studies on infants and their maternal attachment. He explained attachments between children and their caregivers as a crucial element of securing the infants' survival; this is supported by Sullivan and others (2011:647). The caregiver provides protection and safety to the child. This is a crucial prerequisite in order for a child to feel secure enough to allow for investigation of its surrounding social and environmental world (Sullivan and others, 2011:647). Bowlby defines four different types of attachment styles, namely secure, pre-occupied (anxious-ambivalent), dismissing (dismissing-avoidant) and fearful

(fearful-avoidant). Depending on which attachment style the mother has, her reaction to illness and handling the caregiving demands differs.

In the recent past, the original scope of attachment theory has broadened and the theory has been applied to attachment of adolescents and adults (Woodward, 2004:53). It has also been applied to chronic pain (Meredith, Ownsworth & Strong, 2008) and to career choices of occupational therapy students (Meredith, Merson & Strong: 2007). Most recently, Meredith (2009) published an article that investigate the consideration of attachment theory in the occupational therapy literature. She highlights that attachment theory can only rarely be found in occupational therapy literature despite its benefits for the profession (Meredith, 2009:285). The literature that covers attachment theory and occupational therapy is still scarce, and the articles that were reviewed indicate that there is a need in occupational therapy research and practice to incorporate attachment theory. When investigating non occupational therapy literature, sources were found that support the potential that attachment theory has for occupational therapy interventions. Hunter and Maunder (2001:177) have described attachment theory as a relevant model to assist understanding of how people respond to stressors and how occupational therapists can apply it to facilitate coping with the stress that is experienced. As suggested by Meredith (2009:290), 'attachment theory could be a valuable tool in the clinical reasoning process' as it could enable occupational therapists to predict 'specific needs and preferences of different individuals'. The researcher feels that her study could make a contribution to the usefulness of incorporating this highly applicable theory into occupational therapy science and practice.

As attachment theory is an important part of the theoretical framework of this study, the terminology requires brief explanation. Winnicott's concept of holding has an emotional and a physical component that are crucial to be mindful of. As described in Abraham (2007:193), the emotional holding is to be understood as 'holding-the-baby-in-mind in combination with the physical feeding, bathing, and dressing'. Winnicott (1965:147) describes 'holding' within the holding environment as the physical component that is constituted by the mother holding her child which is both an expression of her care and an expression of her love. The love that the child experiences in its dependence is crucial for its development. ABI survivor, in effect, reverts to being the 'infant' by virtue of the health condition.

In the following section, attachment theory will be applied to the 'doing' and 'being' of adult maternal caregiving, and it will be illustrated how connected 'being' and 'doing' are in the process of transition between caregiver strain and constructive control of caregiving in the context of ABI .

5.4 Transitions between caregiver strain and constructive control of caregiving

Mothers are usually the ones who 'hold' their children. They are by default the caregivers; this applies as well when the child sustains an injury, no matter at what age. In one of the cases, the mother and father share the caregiving role. The primary caregiving activities and tasks are done by the mother, but she is not the one who holds the ABI survivor emotionally. The 'containing' part of the holding environment is mainly provided by the father. She presented as detached to her role as caregiver and to her son, which supposedly she is only able to do because the 'emotional holding' is provided both to the ABI survivor and to her by the father/husband. This highlights the necessity to understand the concept of the holding environment which, as Winnicott stresses, needs to consist of not just the mother but the parents together. He states that 'the psychological and physical holding an infant needs throughout his development continues to be important, and the holding environment never loses its importance for everyone. The holding environment includes the father, the extended family and society at large' (in Abraham, 2007:193). While the focus of this study is on maternal caregivers, the point raised here is that the holding environment has a crucial operational function carried out by multiple stakeholders concerned with the care of ABI survivors.

Du Toit (2010:71) reports on the socio-cultural expectation towards mothers and their immanent responsibility to be caregivers. They are perceived as caregivers by default. Heard and Lake (1997:3) stress in this regard that 'the capacity for caregiving has been taken as implicit and until recently has attracted little attention in its own right'. The complexity of the caregiving role is so vast though that it is a sheer miracle that so many maternal caregivers cope with their role and demands of becoming a caregiver. According to Winnicott (1965:88), the reason for this may lie in the highly individualized and constantly modified care only a mother seems to be able to provide for her child. Another explanation is given by Okadô (2006, in Fumiyo and others, 2009:278) who describes the

sense of loss mothers often feel when their adult children leave home under normal circumstances. They assume that as a result of this perceived loss there may be a sense of joy in having their son or daughter return to their home, return to their care.

The point here is that, in line with Bowlby (1988), mothers providing care to adult children recapitulate the earlier attachment. The mutual attachment between child and caregiver 'ensures that the pair maintains contact' (Sullivan and others, 2011:643), which informs the reciprocal attachment. The quality of care provided by the mother is crucial for the development of the infant's emotions and cognition (Sullivan and others, 2011:643). Sullivan and others describe four attachment styles that lead to certain behaviour in the child and the mother (as she has an attachment style once obtained from her own mother). If the attachment is insecure, it 'appears likely to predict problematic adjustment to illness and a greater susceptibility to experiencing poor outcomes from a range of treatment interventions' (Meredith, 2009:289). Meredith advises that clinical interventions by occupational therapists would benefit from understanding this body of evidence (2009:289) as it can 'support clinical reasoning across all fields of occupational therapy practice [...] and improve our understanding of individual health behaviours, emotions and beliefs' (Meredith, 2009:285). How mothers understand their role of being caregivers and how they perform their caregiving occupations can be understood in much more depth if the framework of attachment theory is implemented within the occupational therapy service provision. By understanding the style of attachment of the mother, her behaviour can be explained and, if needed, her attachment style can be addressed and modified.

It is evident from both clinical practice and the literature that the mothers become primary caregivers in most cases, but this should not be expected to occur without the mother's decision and cognisance of the demands and need for acknowledgement of the hardships and joys involved. This is where an occupational therapist can act as a facilitator to guide the caregivers through the different stages in the process of reacting to the ABI (Fumiyo and others, 2009:277), as described below.

5.5 Occupational imbalance

'Family members provide the primary support system for the patient and new patterns of living have to be developed by the family in order to achieve a balance in the altered situation' (Verhaeghe and others, 2005:1004). According to Hanks, Rapport and Vangel, (2007:50), 'social support reduces the adverse influence of stress associated with caregiving'. However, the demands that the caregiving role places on the caregiver are multifaceted, and to achieve balance can be a great challenge for the caregiver. According to Pickens, O'Reilly and Sharp (2010:238), most of the caregivers in their study were faced with the stress of maintaining different demanding roles alongside each other, such as being caregivers to their injured family member, providing care to other members of the family, as well as holding up their roles as workers, bread winners and friends. All these stressors combined can amount to an occupational imbalance being experienced by the caregiver. All mothers in this study expressed a constant worry for their children's wellbeing as well as sadness. It was repeatedly stated that the mothers primary role was that of being a caregiver. Only once their duties in this regard were completed would they consider other tasks. With regard to their own interests, each one of the four participants explained that they are trying to get back to engaging with their personal interest but they either cannot find the time or they are too tired at the end of the day. As indicated by these examples, occupational imbalance can be caused either by emotional difficulties that arise from the maternal caregiver as container or it can occur as a result of experiencing difficulty in attending to the role demands of the maternal caregiver as conductor. Dealing with the impact of brain injury as a mother requires a lot of emotional, psychological and physical strength. In order to sustain their ability to consistently provide care it is crucial that these mothers maintain occupational balance.

With regard to the awareness of the mother towards her caregiving role, she needs to take it on and execute it in order to perform the occupation of caregiving. The virtue of being a mother defines her being to a large extent and particularly her being a caregiver. Winnicott (1971:130) stresses 'the need for the individual to reach being before doing: 'I am' must precede 'I do', otherwise 'I do' has no meaning for the individual'. The researcher believes that this is a crucial prerequisite for the occupational balance of the caregiver. The demands of the caregiving role and occupation can be so high that occupational imbalance occurs, which then affects the congruence between different occupations of caregiving and the mother's values. To be conscious and reflective as a caregiver informs the caregiving

and promotes a supportive and conducive environment for the caregiver and the ABI survivor.

Lastly, it is important to also consider what emotional state the caregiver was in prior to the onset of injury. There may have been emotional strain or imbalance before, and dealing with the impact of ABI is an added emotional impact in the caregiver's life. This can lead to occupational imbalance without even having acted on it yet and informs the needs for maternal caregivers to be considered as second-order patients within the occupational therapy service provision.

5.6 Occupational imbalance and the five stages of reacting to brain injury

Five different stages of reacting to brain injuries were described by Douglas (1990, in Fumiyo and others, 2009:277). He explains that 'family members of people with traumatic brain injury have typically reacted in the following five stages: shock, expectation, reality, grief, and adjustment'. These stages inform mothers in their role as containers and conductors and they may be linked to the phenomenon of occupational imbalance. The complexity of brain injury is extensive and the process of adjustment difficult, as the mothers is not adjusting to a 'simple' injury such as a fractured leg that happened to their child. In this case the injury has a very clearly defined impact on the body, leads to clearly defined functional impairments in the patient for a certain period of time and within a fairly defined time frame that the injured person may require care for. From the onset it is to be expected that the injured person will make a full recovery and the provider of care will be able to return to 'normality' just as before the incident.

In the event of an ABI though, none of these facts apply. The injury is often diffuse and impacts on multiple facets of the person and their behaviour. The functional impairments are various and subject to change. They change because of healing or learning taking place but also because ABI survivors can have fluctuating daily (physical, emotional and behavioural) health changes that impact on their level of functioning. The caregiver needs to adjust constantly to the differing needs and demands of the ABI survivor. The length of care required cannot be estimated by anyone in the health care provider team and places high levels of uncertainty on the caregivers' lives as well as the lives of their other children. The adjustment process therefore becomes difficult as the five stages that were described

above do not occur in sequence until adjustment is reached. Research shows that the different stages occur in a cyclic movement that constantly moves between acceptance and coming to terms with what has happened, and non-acceptance that can be characterized by shock and denial (Fumiyo and others, 2009:285). It is almost impossible to determine the time required for adjustment to ABI due to the many internal and external factors that influence this process and are not controllable. As much as the caregiver is trying to adjust, things happen (accidents, health deterioration, social/ family relationship strains, financial problems etc.). In none of the four participants' cases was adjustment evident. Each participant presented with a transitional process between the above-mentioned different stages, although the stage of shock appeared to be processed (most likely linked to time span since onset). Erika expressed how she has certain expectation towards her son Shawn to understand his limitations, but then reality presents a scenario that does not reflect his understanding (see example of toilet scenario under chapter 4.3.4). She explained that the situation described made her think and worry and cause sadness, but ultimately, through a process of adjustment, she reacted with understanding and acceptance to his irritability and lack of understanding.

5.7 Maternal caregivers as second-order patients

According to the attachment style of the mother, her state of health can be affected. Insecurely attached adults show poorer health in comparison to adults who are securely attached (Meredith, 2009:289).

From the findings emerged that mothers felt they had 'little time to rest', which echoes Du Toit's (2010:67) findings that 'caring for their children consumed so much of their time, that there was hardly ever time to rest'. One mother spoke about having lost her freedom which resonates in the literature, such as in Braine (2011:160) who stated that in her study 'the carer expressed a feeling of lack of freedom and being trapped'. Soliswa repeatedly stated that before her son's ABI she used to be free but now she is not free anymore. The constant worry about their children's safety led to the mothers never or hardly ever taking time for themselves to relax or do leisure activities they used to enjoy. Mothers in this study were aware of the need to take time off but only seldom actually put this into practice, for lack of time or fatigue or not wanting to let their child out of their sight (Babalwa and Soliswa).

Mothers reported that the occupation of caregiving 'is not easy'. In fact, most of them said that it is hard, that it can be depressing and frustrating. It was equally stressed that caregiving is time-consuming and family members often do not understand the impact that the injury has on them as caregivers or what the injury actually entails for the survivors themselves. This is in line with findings by Wongvatunyu and Porter (2008:321) who stated that the lack of understanding of other family members resulted in conflict within the family.

When looking at mothers in society, it has to be stressed that society expects them to take on the occupation of being the primary caregiver in the case of injury to their children. This is a great expectation the mother has towards herself which can lead to strain, paired with the strain of having to perform the caregiving tasks.

In addition, Porter and Kelso (2008:xiii) indicate that society's perception of the mothering role has changed drastically over the years. When in the 1950s/60s a mother who stayed at home to look after her children was well respected, these days mothers have to balance the role of being the caregiver with that of being a successful worker too.

In the case of providing care to a disabled child, the mother experiences herself engaging in an occupation that is connected with the absence of value that is attached to people with disability as highlighted in an article by Green (2007:151). She explained society's reaction to parents who are being positive towards their disabled children. They tend to be perceived as removed from reality and not wanting to accept that their child is inferior as a result of their disability (Green, 2007:151). Lastly she concludes that 'not only has traditional scholarship failed to give credence to parental experiences of benefits, it has also tended to focus on the individual, emotional burdens of having a child with a disability rather than on the burdens imposed by negative public attitudes toward disability and inadequate support for the expensive and time consuming task of caring for a child with special needs' (Green, 2007:151).

It is highly unethical to impose a role as complex as that of a caregiver on these women without even considering their feelings towards it. Their concerns, needs, worries and desires need to be taken into consideration by service providers, as attainment of positive rehabilitation outcomes can only take place if maternal caregivers are being considered accordingly. Even if consideration of the perspectives and concerns of the maternal

caregiver may not lead to a different outcome for the ABI survivor, i.e. if a mother states that she does not want to be a caregiver but there is no one else to provide care or the financial situation does not allow for a care facility, at least the mother's needs have been considered and acknowledged and a possible enhancement or facilitation towards recognition of existence of positive aspects of caregiving can be attempted.

One of the positive aspects associated with ABI has been indicated by Wongvatunyu and Porter (2008:322) who observed that 'some mothers perceived increased closeness within the family after the injury'. Green (2007:159) reported similar findings, stating that their children's disability brought to them a realization of what really matters in life, which made it easier for them to deal with the hardships that come along with it. This was voiced by three of the four participants who all stated how happy they are to look after their children and who emphasized the positive aspects of caregiving.

Occupational therapists have the professional scope to address maternal caregivers' needs within their service provision. They can create the space for the caregivers to reflect on their feelings (containing). Caregiving tasks (conducting) can be discussed and facilitated. The opportunity to discuss fears, dislikes, hardships but also to emphasize positive aspects of it can be provided to ensure that the mother's wellbeing is restored or maintained (holding environment) within the demands of the role of being caregivers. This could have a positive impact on attaining positive rehabilitation outcomes for the ABI survivors.

5.8 Resilience

Resilience in occupational therapy is understood as 'a significant factor that influences the balance and the state of being capable/ knowing how to' (CAOT, 2009). Mannion stated that it refers to 'how family members experience a process of constructive change and growth in response to serious [...] disorder in a loved one' (1996:14). One of the participants presented with a remarkable ability for constructive change and expressed that since her daughter's onset of ABI her life had gotten better. In addition, the ABI had a positive effect on the entire family. She expressed how her daughter's illness gave her the power to walk again: *'I want to feel Nobanzi; feel her pain, feel her again. And I did feel her' (Babalwa)*. One of many possible explanations for that could be found in the following quote by Engström and Söderberg (2011:258): 'People are bound to one another by love,

sympathy, and solidarity. These ties are formed spontaneously or socially, and it is these ties that constitute a person's existence'.

Even though Babalwa gave such a positive account of her capabilities and acceptance of the impact that her child's ABI had on her life, she is still experiencing caregiver burden. The feelings of loss and hardships were voiced by her as well, apart from her mainly positive accounts. The crucial point for occupational therapists working in the field of neurology is the importance of recognizing mothers' resilience to conquer adversity while acknowledging the existence of burden and painful feelings (Abelenda, 2003:29).

The extent of dedication Babalwa showed highlighted the **resilience** that she has as a mother and as a caregiver. She shared her memories from when she received the doctor's phone call when Nobanzi sustained the ABI and she went to the hospital to go and see her: *When Nobanzi was in hospital, I started walking again. I am the only one, I am her mom. The Doc phoned: 'You can come'. When I get to the hospital there is a wheelchair. I said 'no, I want to walk with my stick. I want to feel Nobanzi; feel her pain, feel her again'. And I did feel her. Gave me power to walk.*

5.9 Summary

This chapter discussed the findings and how the 'doing' and 'being' of caregiving are interrelated. It highlighted the need to incorporate maternal caregivers as second-order patients into the occupational therapy service provision and discussed different factors that place strain on mothers who become caregivers. It also emphasized positive experiences of caregivers.

CHAPTER 6: RECOMMENDATIONS AND CONCLUSION

This chapter presents recommendations, limitations of the study and concluding remarks.

6.1 Recommendations

6.1.1 Inform health care providers

Health care providers across professions would benefit from increased awareness of and knowledge about maternal caregivers' needs as potential second-order patients. By incorporating this information into their area of practice and expertise, they will gain a better understanding of the demands that are placed on maternal caregivers providing care to ABI survivors. Furthermore, they will be able to incorporate the caregivers' needs as second-order patients into their service provision. To impose a role or to assume the needs of mothers of ABI survivors is highly unethical and also not conducive to the creation of an optimal holding environment and ultimately for the best possible rehabilitation outcomes for the ABI survivor. Taking into consideration the caregivers' needs will have a positive effect on the overall service provision to the ABI survivor. The researcher is therefore promoting the application of Figure 5.1 (Being The Holding Environment-Diagram) as a schematic tool for explaining aspects of the caregiving process to mothers as second-order patients. Clinical team members can also use the diagram to facilitate conversations with mothers throughout the long journey of rehabilitation, creating opportunities for shared learning, support and reflections on the multiple transitions and oscillations associated with caregiving.

6.1.2 Occupational therapist conversations with mothers and other family members

In particular, Figure 5.1 is a highly useful framework to guide occupational therapists in their work with maternal caregivers as occupational beings. Figure 5.1 could be used firstly as an assessment tool for identifying occupational challenges faced by potential second-order patients, secondly, as a tool to guide an occupational therapist to support maternal caregivers in performance of caregiving and other occupations and thirdly, as a framework to give theoretical structure to therapists' intervention for second-order patients.

- As an **assessment tool** it can guide open-ended questions by the therapist and discussions with mothers 'to explore any similar changes that the mother has perceived' (Wongvatunyu & Porter, 2008:326). How does the mother perceive her role as container and how does she perceive the conducting aspect of being the holding environment? Occupational therapists are equipped to assess the mother's occupational well-being. By identifying stressors and the mother's possible needs, occupational therapists can assist with skills acquisition in order to better handle the role demands of having become a caregiver. They can furthermore provide the necessary education to better understand brain injury and its impact on the environment, as well as alert the mothers to the need to look after themselves in order to be able to provide good care to their adult brain injury survivor children. The maternal caregivers' desire to be involved in the care of their adult ABI survivors should be investigated, not assumed, and Figure 5.1 helps in this regard.
- As a **framework for supporting** mothers as second-order patients, Figure 5.1 can be useful as a guiding structure to have a conversation with the maternal caregivers. It can be used to highlight the different stages and processes that occur when mothers become caregivers and second-order patients. Mothers can be advised as to where in the process different health professionals including the occupational therapist may become involved and what other possible resources of support are available.
- The processes of transition and oscillation can be highlighted by the occupational therapist as a phenomenon that commonly occurs in mothers, and transitions between strain and constructive control can be explained in relation to occupational balance. The diagram would help mothers to visualize the processes and possibly aid their reflections about the health and well-being benefits of occupational enrichment.

The above indicated use of figure 5.1 should be extended to all the role players of the holding environment, i.e. including the father and the extended family. Fumiyo and others (2009:277) suggest that 'the family's response should be an important focal point in the rehabilitation of people with brain injury'. Awareness for caregiving of adult ABI survivors

should be raised to alter society's pre-conceived perceptions and expectations which are characterized by intolerance towards people with disabilities (Schultz, undated).

This appears to be a valid form of implementing the findings of this study into the clinical practice of occupational therapists working with people and their families post ABI.

6.1.3 Make benefits of caregiving known

Benefits of caregiving needs to be emphasized by all health care providers. Caregiver burden is commonly assumed but over-emphasized by health care providers and the general public/ society. ABI is generally perceived as a tragedy. This is not a conducive assumption to use in professional practice to promote adjustment and wellbeing in the caregiver as well as in the ABI survivor post injury. Green (2007:151) advises that 'there is mounting evidence in the literature on loss and trauma that finding benefits can have a positive impact on both emotional and physical health. If parents of children with disability are repeatedly discouraged from finding and acknowledging the positive aspects of caregiving, they may be denied the potentially positive consequences of doing so'.

6.1.4 Further research

Further research could be conducted in the applicability of the theoretical framework of attachment theory to occupational therapy. An interesting tool to investigate for applicability in the clinical field of occupational therapy is the 'Adult Attachment Interview' (Stevenson-Hinde, 2007:340). It is an assessment tool to inquire about the emotional communication in relation to parent's attachment patterns, which would give valuable insight into the mother's state of being that could inform the service provision of occupational therapists. The study could be conducted in a very similar way with fathers and other family members and the experiences of caregiving as lived by the entire family could be investigated (see Chapter 6.2: Limitations).

Further studies would bring more knowledge of the experiences of families after brain injury. An increased awareness of the needs of caregivers of ABI survivors can contribute to an improved quality of life for the ABI survivors and their family and friends as they all form part of the holding environment for the ABI survivor.

6. 2 Limitations of the study

Maximum variation sampling was not sufficiently addressed in this study. Only mothers' perspectives were obtained, but the holding environment consists of a wider system of reliable holding that should be taken into account as well. One participant had a very involved husband which presumably altered her role perceptions. Bowlby suggests that the holding environment should consist of both parents. He speaks about 'the provision by both parents of a secure base from which a child or adolescent can make sorties¹⁵ into the outside world and to which he can return knowing for sure that he will be welcomed when he gets there' (Bowlby, 2005:12). This study should possibly have considered both parents as part of the holding environment as the caretaker's spouse / father of the ABI survivor is a crucial part of the family, i.e. the holding environment. More depth of data could have possibly been obtained by including the spouses.

6.3 Conclusion

This collective case study was conducted with the intention to increase the knowledge base for incorporating maternal caregivers as second-order patients in occupational therapy and other health professional interventions, such as physiotherapy, speech therapy and others. The research intended to provide a better understanding of maternal caregivers' role demands and the occupation of caregiving. The insight gained into mothers' perceptions will inform occupational therapists in their service provision to ABI survivors and their families, especially their mothers. The five stages of shock, expectation, reality, grief and adjustment emerged as crucial stages in the transition process. Oscillation was observed between acceptance and feelings of ambivalence towards the caregiving role and the demands arising from caregiving as occupation, and between feelings of capability and in-capability. Providing care to ABI survivors in essence involves 'being a holding environment', a life position that comes naturally to some maternal caregivers while raising ambivalence and resistance in others. It is at this juncture that secondary intervention by rehabilitation professionals including occupational therapists

¹⁵ 'Sorties' is defined as 'excursion/ expedition' (Mirriam-Webster Dictionary). According to the Mirriam-Webster Dictionary it originates from the french 'sortir' and refers to 'going out, leaving'.

can facilitate role adjustment and in so doing promote the well-being of caregivers, families and the ABI survivor.

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APPENDIX:

Appendix A: Approval from the Health Research Ethics Committee

UNIVERSITY OF CAPE TOWN



Health Sciences Faculty
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za

07 March 2012

HREC REF: 107/2012

Ms I Steinhoff
c/o Ms A Sunday & A/Prof E Duncan
Occupational Therapy
Health & Rehab
F-Floor
OMB

Dear Ms Steinhoff

PROJECT TITLE: CAREGIVING OF ADULTS WITH ACQUIRED BRAIN INJURY (ABI) A CASE STUDY OF MOTHERS' PERSPECTIVES.

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year till the 30th March 2013.

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read 'M Blockman'.

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

..thomas

Appendix B: Information letter for research participants

University of Cape Town

Department of Health and Rehabilitation Sciences

Information letter for participants of the study carried out by Inge Steinhoff (STNING004)

Topic of study: Caregiving of Adults with Acquired Brain Injury (ABI):

A case study of mothers' perspectives.

HREC REF: 107/2012

Researcher, Inge Steinhoff: ***

Supervisor, Amshuda Sunday: ***

Chair of the human research ethics committee, Professor Marc Blockman: ***

Date:

Dear research participant,

You have been contacted to participate in this study as you were identified to be a suitable participant for the above-mentioned topic of inquiry. I am looking for four mothers of adult brain injury survivors who I will interview in the process of collecting data. I would like to thank you for showing an interest in participating in this research study and I, the researcher, will take this opportunity to present myself and my study to you in a few short words.

I am an occupational therapist enrolled in a Master's programme at UCT and this is our final dissertation to obtain an MSc in Occupational Therapy. My professional interest as an occupational therapist and Master's student lies in neurological rehabilitation, and I am particularly interested in the experiences mothers have who are caregivers of adults who sustained brain injuries. I have been working with brain injury survivors and their families for the past 10 years and would like to further my knowledge on this particular topic with the help of your participation.

Procedures that will be followed:

I will arrange for one to two interviews with you that will take place at your convenience, in your home environment if suitable to you. If you prefer to have the interviews at a neutral space, arrangements will be made to accommodate your wish.

Each interview will take approximately 60 mins, with the first one taking an additional 15 mins to familiarize ourselves with each other and for me to collect some personal information about you.

Interviews will be audio-recorded to allow for me to transcribe and analyse after the interview.

What is required of you:

You will need to speak to me about your experiences of being a caregiver of your adult son or daughter who has sustained a brain injury in his/her adult life. I may ask you some questions to get more information on some parts of your personal story.

At the initial visit, we will have some time to familiarize ourselves with each other. You can ask questions about the study and you will sign a consent form that allows me to interview you.

Should you wish to discontinue your participation at any given time throughout the study, you can withdraw without giving any reason for your withdrawal.

Confidentiality:

The information that you will give me will be used exclusively for my Master's dissertation at the University of Cape Town. All names of places and people will be changed in the dissertation to ensure your confidentiality. All records taken in the interviews or elsewhere will be stored safely at my home and will only be accessible to myself. Your name and personal details will not be stored in the same place as the interview notes to avoid breach of confidentiality.

Benefits & risks of participation:

By sharing your personal story with me, I will be able to learn about the experiences, needs, joys and hardships of mothers who become caregivers. With this knowledge, occupational therapists and possibly other health practitioners will be able to gain a better understanding of your and other mothers' needs. This may help in the long term to improve services for mothers and the brain injury survivors who are in a very similar situation to you and your loved ones.

By sharing your personal story with me in the interviews you may experience some emotional reactions. You may feel sad or angry. If you feel you need support, I will refer you to the support group for brain injury (BIG) or to a social worker in your area.

As a researcher I will not be able to provide you with advice or solutions regarding the problems you are experiencing. I will also not be able to provide your son or daughter with therapy but I will make the necessary arrangements to put you in contact with people who can be of help to you. You will not be paid any money for taking part in this study and no costs will incur from your participation.

Best regards,

Inge Steinhoff

Appendix C: Informed consent form

University of Cape Town
Department of Health and Rehabilitation Sciences

Informed Consent

I, _____ (Name and Surname) give my consent to participate in the study titled "Caregiving of Adults with Acquired Brain Injury (ABI): A case study of mothers' perspectives", HREC REF: 107/2012.

The aim of the study and the benefits and risks involved were explained to me.

I understand what will be expected of me during the study.

I understand that my participation is voluntary and that I can withdraw at any time without giving a reason for my withdrawal.

I understand that I will not receive money for the study and that I will not have to pay anything to participate in it.

I understand that the researcher will not provide me or my son/ daughter with therapy or advice but that I will be referred to someone else at my request.

I have been informed that the chairperson of the Faculty of Health Sciences Human Research Ethics is Marc Blockman, Committee Room E52.24, Old Main Building, Groote Schuur Hospital. Email: Marc.blockman@uct.ac.za. TEL: 0214066496.

Date

Place

Signature of Participant

Signature of Researcher

Appendix D: Probing questions for interviews

University of Cape Town
Department of Health and Rehabilitation Sciences

Probing Questions for Interviews¹⁶

Introduction: I am an occupational therapist. I am interested in the things that occupy your time, energy and interest every day. I will be asking you questions about what you DO in caring for your son/daughter and how this DOING affects your life as a whole. Do you have any questions before I start?

- When the accident/ incident happened to X it did not just affect him/ her but it also affected your life. I would like you to tell me what has changed in your every day life from before to after the accident? What do you do for X on an every day basis to meet his/ her needs? ¹⁷
- How do you feel having become a caregiver?
- Has the way you live your life changed from before the accident? (possible further probes: How has it changed? Do you miss your old life?) ¹⁸
- In your day caring for X, is there time for you to pursue your own interests?¹⁹
- In what way does your relationship with X differ now to what it was like before the accident happened? Does your role as a mother differ in any way? ²⁰
- What have you learnt about yourself/ about X/ about others in the home a result of giving care to X?

¹⁶ Questions were changed in wording and full questions or parts were added in correspondence with supervisors.

¹⁷ Questions about what mothers do on a daily basis were introduced by adding references to impact of brain injury on survivors AND the mothers. Also concept of 'change' was added to the initial question.

¹⁸ Emphasis on 'change' was added. Question about what makes the mothers happy or sad about the role of being caregiver was changed to: 'do you miss your old life'?

¹⁹ Question did not feature in pilot interview schedule

²⁰ Initially it was assumed the role of caregiver has changed the mother's life. It was re-worded to inquire if the role as a mother differs.

- Where do you find your support?
- If you had to give another mother in your position advice about caregiving as an occupation, what would you say to her?
- Is there anything else you would like to share with me about your experiences?

Appendix E: Baseline data sheet of research participants

University of Cape Town

Department of Health and Rehabilitation Sciences

Baseline Data Sheet of Research Participants

Participant:	
Area:	
Age of mother:	
Marital status:	
Age of ABI survivor:	
Time since injury:	
Duration of caregiver role:	
Number of other children/ people in the home requiring direct/ indirect caregiving:	
Ages of other children:	
Number of people in the household:	
Family/ friends supporting:	
Formal support:	
Level of education:	
Employment:	
Income:	
Health of caregiver:	

Appendix F: Analysis of audit example

Theme: being the holding environment

Category One: maternal caregivers as containers

Subcategory One: Accepting States

Data:

'First thing I settle him in the morning. Have his breakfast, see to him, room is clean, everything is clean. Then I know he can do anything he wants to do. When he is relaxed, I am also relaxed. If he is not relaxed, I am not relaxed' (Erika).

'When he is getting better, I am also getting better. When I see my son is recovering, I am also recovering' (Soliswa).

'The relationship with Nobanzi was not so good in the first time when she did not have the accident. We fight a lot 'cause she go out a lot with her friends. But now my relationship with Nobanzi is daughter and mom. Nobanzi did not give me a lot of time to talk sometimes. But now I can see I am a mom. The change happened while Nobanzi was in hospital. I was the only one visiting her. I have re-connected with all my children. I am a very strict mom but now my children can talk to me. They come to me now. Very positive change. Nobanzi gave us a very positive change'.(Babalwa).

'Sometimes when people talk about the son [who was shot 10 years ago] I would shut down, but Nobanzi gave me that life back. I can talk now about him again. I can look at his pictures. She gave me that smile back'.(Babalwa).

'He sometimes has more patience with Shawn (than she herself). When there was a time we had to take Shawn to the toilet, he did not moan. He did it for him. Now, the other day he took Shawn for a walk to fetch Brenda from the crèche with his walker. It was about a five minute walk but Shawn takes longer. It was a windy day. He has patience with him' (Erika).

'You gotta believe. You believe in God, that is the main thing. You get a lot of strength...that helps a lot...and the church too. They are very good. I am a Christian....it is very good... [...] If you can find the lord it helps a lot. It is a personal feeling that you feel, not religious. It is becoming a Christian. Accepting Jesus as your saviour. You know, you still have your up and downs...you don't have to kneel down...you talk to him all the time. That's what you do' (Sarah).

'I just pray and ask the Lord just to give me strength and that makes it easier. If you haven't got faith. There is people out there that is praying for me' (Erika).

'When Nobanzi was in hospital, I started walking again. I am the only one, I am her mom. The doc phoned: "You can come". When I get to the hospital there is a wheelchair. I said "no, I want to walk with my stick. I want to feel Nobanzi; feel her pain, feel her again". And I did feel her. Gave me power to walk' (Babalwa).

'I think Nobanzi gave me that second life again. She gave me that second life' (Babalwa).

'I say my role as a mother to Nobanzi I am very proud of myself. I am very proud of myself because I can talk to her now. I am very proud that I can give her some time advice' (Babalwa).

'I always worry because he got fits after the accident. But before the accident there was no fits, the epilepsy. He has got that. I am so worried. Maybe nobody home. He stay alone sometimes... I am also worried maybe he fall again...and it can happen again...I don't know' (Soliswa).

'He wants to be on his own but he can't. He thinks he can be on his own but he really is not at the stage where he can be on his own, 'cause I can see that. He can't. He needs help. He was... he is... he was a very independent person. He wants to be on his own but he can't stay on his own because the girlfriend left him, so there is nobody that is going to care for him. We can't trust anyone to care for him. So I say to him he must stay as long as he can until the day that he knows he can stay on his own. If he had someone caring like I care for him, then I would let him go. But he must find the right person' (Erika).

When asked how she would feel about Shawn moving out she replied: 'If he had somebody caring like I care for him, then I would let him go. But he must find the right person' (Erika).

Subcategory Two: ambivalent states

Data:

'I suppose I could say I learned who my friends were... what my family is like sometimes... I mean, my sister in law watched, looked after him once with her husband...it was just one night...and the next morning they could not get home quick enough. You know...they were really going...you learn a few things' (Sarah).

Sometimes the other brother and the sister, sometimes they don't understand it. And when I explain to them sometimes when they have a talking or a little fight, when I try to, suppose to stop them even when he is wrong because I am worried they don't understand the situation of him. When he is cross you are not supposed to argue with him. Let him to. Told them not to argue with him...but my other kids they don't think about that when they are fighting. They don't think that he has a brain injury. They don't think about him' (Soliswa).

'I think in the beginning you do get depressed. You know, it will depress you. Because you think about how Robert was. He was a very good-looking, athletic type. Always out on the sea and everything and now his life has changed right over to sitting in a wheelchair' (Sarah).

'When I look at Nobanzi, she is not the same child as she was before and that hurts me very much. Sometimes when she talks to us it is like a little girl of six or five years old and that hurts me very much' (Babalwa).

'There is hardly time for myself. After caring for Shawn it's my own work that I have to do. If I get a rest during the day it is about for an hour, for the whole day before I go to bed at night. After the day ends with Shawn and myself, then I am very tired and I don't feel for anything. I just want to go to bed' (Erika).

'Before, you know, I was free. Because at home there is no...all my children are fine. But after the accident... [...] when I am not home I was worried since the accident. I am not free. But, I lost that freedom and I don't care. You see, I lost it but I am with him... I feel happy because I said then, when he was in the ICU, I said "God, give him a chance. I don't want him to die. I don't care how he is, if he can't walk or something happen to him. I want him back. I will look after him with all my heart". I am happy, Inge, to look after him. It makes me happy. Because, to show him I do care about him and I love him. It is not difficult' (Soliswa).

'I used to go out ...and come home late at night or in the morning but after Nobanzi became sick that changed my life' (Babalwa).

'Someone else would have put their child in a home after three years and it would affect their marriage' (Sarah).

'Sometimes when we talk to Nobanzi she keep quiet . Then I ask Nobanzi why do you keep quiet? Then she said, no, I just keep quiet. Then I become a little bit depressed. Why is the child keeping quiet? (Babalwa)'.

'Sometimes you get angry and then you say "behave yourself" and you really want to ...I can understand why some people... you know the caregivers at the homes, they want to throttle them...those old people they look after... but as I say... it could have been a lot worse... And then... And D (husband) wanted him home. No, he did not want to put him into a home... [...] Maybe I would have liked to put him away but Douglas²¹ (husband) would have never liked... ' (Sarah).

When asked is she would now go out and meet her friends she replied: 'I don't think so. I am afraid maybe Nobanzi will get sick again. Sometimes when she is going to her friends I phone her about 15 minutes. You must come home. Because I am afraid maybe something will happen to her. Very protective' (Babalwa).

'There is hardly time for myself. After caring for Shawn it's my own work that I have to do. If I get a rest during the day it is about for an hour for the whole day before I go to bed at night. After the day ends with Shawn and myself, then I am very tired and I don't feel for anything. I just want to go to bed' (Erika).

Appendix G: Probing questions for pilot interviews

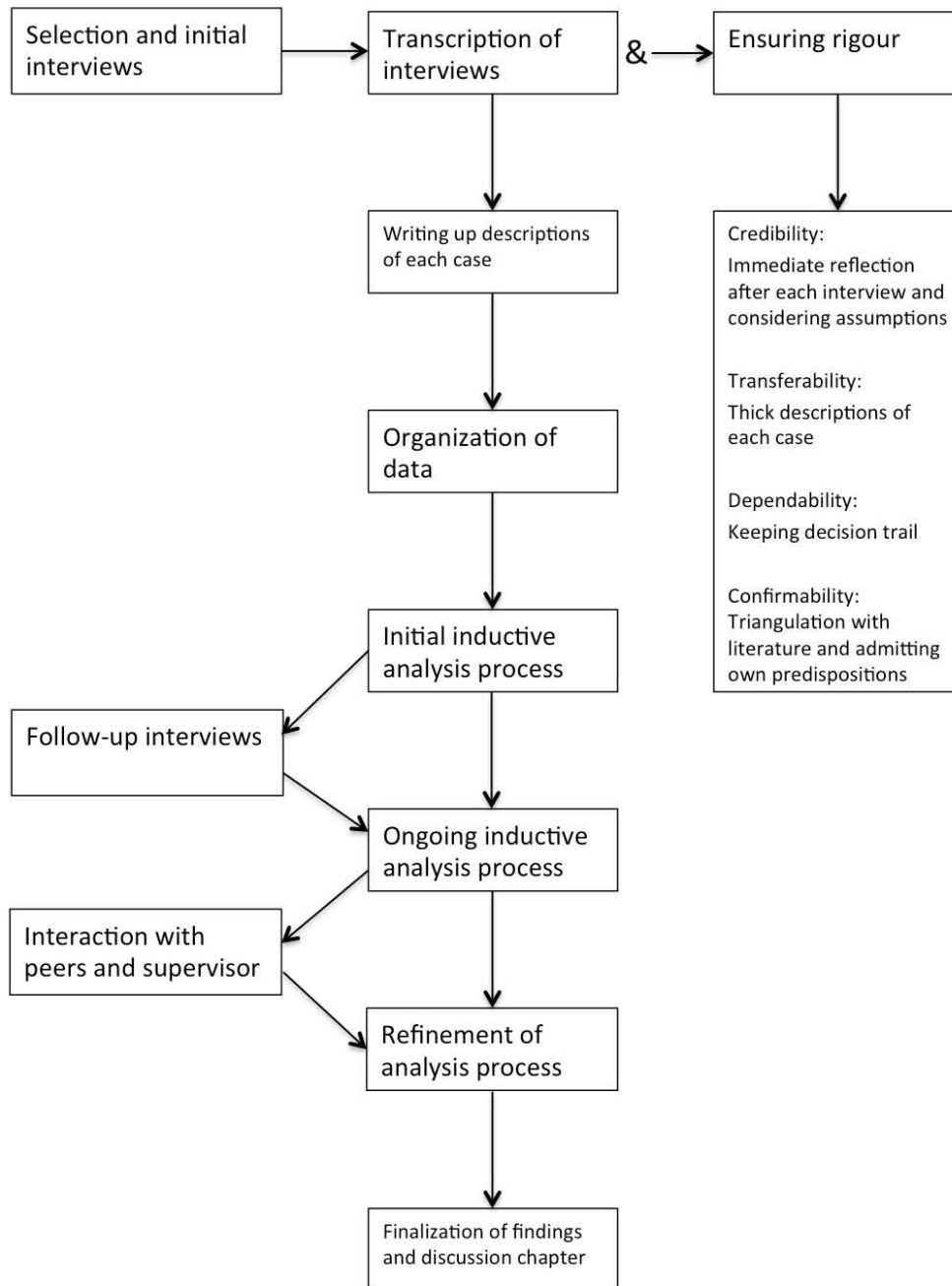
University of Cape Town
Department of Health and Rehabilitation Sciences

Probing Questions for Pilot Interviews

Introduction: I am an occupational therapist. I am interested in the things that occupy your time, energy and interest every day. I will be asking you questions about what you DO in caring for your son/daughter and how this DOING affects your life as a whole. Do you have any questions before I start?

- What does caregiving entail for you? You can start by describing the activities and tasks that you perform every day in meeting the needs of X.
- What do you like/dislike about these caregiving activities?
- How do you feel about having become a caregiver? What is difficult or hard about it and what makes you happy or sad about your role as a caregiver?
- What have you learnt about yourself/ about X/about others in the home as a result of giving care to X?
- If you had to give another mother in your position advice about caregiving as an occupation, what would you say to her?
- What has changed in the way you spend your time, energy and interests since you have been caring for your son/daughter? The changes I am interested in are related to your role as a caregiver and how it has affected your various other roles
- Is there anything else you would like to share with me about your experiences?

Appendix H: Audit trail



Appendix I: Researcher biography

Inge Steinhoff is the founder and owner of a private occupational therapy practice in the Cape Town. Her practice, *Neuro Rehab at Home Cc.*, provides neurological rehabilitation to adults who have suffered stroke, traumatic brain injuries or other neurological diseases and degenerative conditions. *Neuro Rehab at Home Cc.* was founded in 2007, and Ms Steinhoff is currently the practice owner and manager as well as an active clinician in adult neurological rehabilitation. Her practice offers services in two private acute hospitals, one private sub-acute facility, and to private patients in the form of home-based rehabilitation.

Before she started her own practice, Ms Steinhoff worked in a private practice for adult neurological rehabilitation in the southern suburbs, South Peninsula Rehab, providing interdisciplinary outpatient rehabilitation. Ms Steinhoff started working here shortly after she moved from Cologne, Germany, to Cape Town, South Africa, in 1996.

In Germany she had been practicing for four years in a sub-acute early rehabilitation hospital in Cologne where the multi-disciplinary team worked as a close unit and with a family-centered approach to rehabilitation. Family meetings were held regularly, and family members were given a voice to express their needs and concerns in the rehabilitation process. This is where her interest in caregivers and their needs started. Different care options post discharge would be considered, and families had a variety of options that were in most cases subsidized by the national health system.

At the onset of her work in Cape Town, Ms Steinhoff became aware of the shortage of institutions that provide care, the high costs involved with a facility-based care setup, and the interrelatedness of income and access to care and rehabilitation services. Her interest in caregiver well-being increased within the South African context and it led to her writing her Master's thesis in occupational therapy on experiences of mothers who become caregivers of adult brain injury survivors. While doing her coursework and writing her Master's degree she fell pregnant and gave birth to her daughter in 2010. This influenced her understanding about caregivers significantly, in particular maternal caregivers. This is where she started forming an idea about the complexity of being a mother and acting as a caregiver, even though her experiences derive from providing care to a healthy three year old.

Ms Steinhoff resides in Observatory, Cape Town, with her partner Ricardo and their daughter Filipa, together with their two dogs, Piloto and Charlotte.

Appendix J: Supporting organizations for brain injury survivors, friends, family and caregivers.

A few supporting organizations for brain injury survivors and their loved ones as well as caregivers are existent in Cape Town:

- The Panorama Psychiatry & Memory clinic (PPMC), which offers support groups guided by psychiatrists, neuro- psychologists and an occupational therapist. They can be contacted under 021 930 2177 or www.gomemory.co.za.
- Groote Schuur hospital offers an outpatient clinic support group as well as a group that addresses memory problems due to brain injuries. Their contact details are 0860 110111.
- Alternatively, there is the Brain Injury Group (BIG) which is run by Jenny Roos and provides brain injury survivors and family members with support. Their contact details are 021 930 2177 or 082 490 6153 or jennyroos@telkomsa.net.
- Headway – The brain injury association is another valuable resource but has no offices in Cape Town. They are located in Gauteng and KwaZulu-Natal only.
- Online resources that provide valuable practical information around brain injury and the care requirements can be accessed at:
 - www.stroke4carers.org
 - www.biausa.org
 - www.caregiver.org