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Indefinite Loss:
Parent Caregivers' Experiences of Caring for Their Adult Child
in the South African Context.

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A dissertation submitted in fulfilment of the requirements for the degree of
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Declaration

I declare that:

“Indefinite Loss:

Parent Caregivers’ Experiences of Caring for Their Adult Child

in the South African Context”

is my own work, that is has never been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Ruthann Sedgwick

March 2014

Signed

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No man is an island.

John Donne

This dissertation started almost fifteen years ago when I, as a very young student, was introduced to the world of adult neurogenic communication disorders. My first interaction with a brain-injured person ignited a passion deep within me, not only for the survivors of neurological events but also their supporters. This passion has been fuelled by the incredible input and mentoring I have received from my teachers.

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Not to transmit an experience is to betray it.

Elie Wiesel (1985)

ABSTRACT

While it is recognised that the burden on the caregiver of a person who has suffered a neurological event is great, research into the experience of caregiving and the effects of cognitive-communicative difficulties on intergenerational families is lacking. Studies examining these experiences within a multicultural and multilingual setting such as South Africa are few. The effects of neurogenic communication disorders in family systems also require further investigation. This study explores parent caregivers' experiences of caring for their once-independent adult child, who are now faced with the reality of parenting for the second time. A qualitative research design was employed. Eighteen parents of adult children who have suffered TBIs, strokes or brain tumours were interviewed. The data obtained were analysed by means of thematic analysis. Themes associated with caring for an adult child, specifically in the South African context, are identified and discussed. These themes related to the parent caregiver's experience of loss – loss of their child due to physical and cognitive-communicative difficulties as well as the loss of their own dreams and plans for the future. Multiple roles within intergenerational family systems, support and information are identified as significant factors in either minimising or exacerbating their experience of loss. These themes are explained within a Family Systems Theory framework and assist in identifying both positive and negative factors that impact on experiences of caring for an adult child. It stresses the importance of the implementation of sustainable programmes and support services specifically catering for parents of adult children with neurological communication disorders.

Keywords: caregivers, adult neurogenic communication disorders, quality of life, loss, South African context, thematic analysis, family systems theory.

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CHAPTER ONE

1.1. Introduction

I was very happy because I have two children and they are both grown-up. They had homes and they had started working and they were not my responsibility and this was my time because right through I had been working for them and I had been trying to get them through school. At last I had time for myself. Then she (daughter) got sick.

Participant JJ

The above quote, produced by a participant in this study highlights the particular niche and focus of this study, that being the experiences of a parent caregiver of an adult child. The adult child, once independent and self-sufficient, is now once again dependent on the care of her parents due to a debilitating and sudden neurological event. This study describes the experiences of caregivers such as Participant JJ and the challenges faced when a parent is faced with the reality of parenting for the second time.

As a Speech and Language Therapist working in South Africa today, I am continually reminded of the enormous challenges faced by both individuals who have suffered neurological fallout and their caregivers. Over the past few years, I have noted an increase in the number of parents who are readopting the role of caregiver for their neurologically impaired adult child. This study will focus on these South African parents who are faced with the reality of parenting for the second time.

1.2. Rationale for this study

Although a significant amount of research has been done to investigate the effects that neurological events and their devastating sequelae have on family systems, the focus of rehabilitation following a neurological event or diagnosis is very often on the individual presenting with the communication disorder (Lutz and Young, 2010; Threats, 2010). Threats (2010) states that the needs of the family are seldom adequately addressed and frequently interactions between therapists and family members involve providing information and reviewing home therapy programmes. Laroi (2003) suggests that the therapy required by families who have been affected by brain injuries “is distinct from family education and support in that it involves working toward actual change in the family’s organisation, structure or communication patterns” (p. 176). Specifically related to the current study, the concerns of ageing parents who are now faced with the reality of parenting for the second time need to be investigated and addressed by the rehabilitation team, both in the acute phase as well as in the long-term phases of recovery. In developing countries such as South Africa, professional resources to assist ageing individuals are rare and are frequently associated with high costs (Cohen and Menken, 2006).

There are no known studies conducted in South Africa that have investigated the experiences of parent caregivers resuming the role of primary caregiver to their neurologically impaired adult child. Whereas many studies have examined the long-term toll of coping with a family member’s traumatic brain injury or stroke, studies have not specifically examined the subjective burden and practical difficulties associated with parenting a neurologically impaired adult child.

Not only is the prevalence and incidence of neurogenic communication disorders increasing, but because of improved emergency medical technology, more people are surviving serious health-related events such as strokes and TBIs (Laroi, 2003; Lutz & Young, 2010; Wallengren et al, 2008). The medical emergency is, however, very often over long before the effects of the event are truly felt by the injured individual and their families. Lutz and Young (2010) explain that the resultant physical and cognitive-communicative difficulties require intensive and long-term intervention from rehabilitation therapists as well as family members. Many early studies focused on the impact of physical disabilities of an injured family member on a family. Restricted attention has been given to the impact of cognitive-communicative changes on the family dynamics and individual family members. It may be suggested that because of the importance of communication in developing and sustaining interpersonal relationships, relationships may be negatively affected by the presence of cognitive-communicative difficulties.

In addition, many studies have focused on the immediate needs of caregivers (King & Semik, 2006). Few studies have investigated how the needs and experiences of family caregivers change over time (Thomas & Greenop, 2008). In addition, many studies have explored the experiences of young children with acquired cognitive-communicative difficulties (Bornman & Alant, 2002). Furthermore, attention has been given to the experiences of parent caregivers living with a child with a psychiatric condition (Aschbrenner et al., 2010). Maggs and Laguharne (1996) explain that there is a need to investigate the relationship between informal caregivers and their neurologically impaired family members as they age.

1.3. The setting for the current study

The participants interviewed in this study are all residents of the most densely populated province in the country, Gauteng. According to statistics, Gauteng has a population of approximately 11 million people. This constitutes approximately 20 % of the total population of South Africa.

Although Gauteng is reported to have relatively high levels of medical insurance coverage (approximately 26 % in 2010), only 11 district hospitals are available for those patients who do not have medical aid. Surveys have suggested that approximately 18 to 20 % of South Africa's population have access to private medical funds (Goosen et al., 2003; Levin, 2004). These private medical funds are most often subsidised by employers and are, by default, then only accessible to people who remain in the employment of the company. In addition, Padayachee (2001) cautions that not all members of medical aids are entitled to the same degrees of accessibility. This is in accordance with the ideas proposed by Moorman (2001) and Bateman (2002) - "some exclusive and expensive medical aids provide full cover for all hospitalisation and rehabilitation needs; others provide very basic cover which often is insufficient and results in members having to resort to state-run care when the funds have been exhausted" (as cited by Levin, 2004).

It is further estimated that 7.1% of the GDP is spent on health – assisting the 80 % of South Africans that do not have access to private medical funding and services. These are the majority of South Africans who make use of often limited and under-resourced

public healthcare facilities. Very often the individuals who access and make use of these public healthcare services are responsible for family members' care.

These individuals often form part of intergenerational families within South African communities. For the purposes of this study, the term intergenerational families refers to families in which more than one generation is represented in a residential or home environment. The World Health Organisation (WHO) report that increasingly generations within families are opting to reside together in order to improve support and facilitate better use of financial and other resources within the family. In addition, family caregiving within such intergenerational family systems is becoming more common worldwide (Haberkern & Szydlik, 2010).

The increased need for family members to assume caregiving responsibilities for their loved one may be a result of a family member's neurological event, such as a traumatic brain injury or stroke.

1.4. The neurological event

For the purposes of this study the term neurological event will refer to a traumatic brain injury (TBI), cerebrovascular attack (CVA), cerebral tumour or abscess.

1.4.1. Traumatic brain injuries (TBI)

According to statistics, motor vehicle accidents (MVA) including pedestrian vehicle accidents (PVA) are the leading cause of TBIs in South Africa, accounting for

approximately 50 % of reported TBIs (National Institute for Occupational Health). Alcohol and substance abuse have been attributed to motor vehicle accidents (The Road Accident Report, 2002), particularly involving drunken pedestrians (Goosen et al., 2003) – an estimate of 72 % of adult traffic deaths have been attributed to pedestrian-related accidents (Van Der Spuy & Steenkamp, 1996). In addition, the use and abuse of illicit and over-the-counter drugs have also been linked to an increase in the risk of stroke (Dobbs & Berger, 2009; Kaku & Lowenstein, 1990; Sloan et al., 1991). The abuse of drugs and similar high risk behaviours has also been linked to the transmission of HIV, suggesting a further relationship between stroke and HIV.

Interpersonal violence has long been attributed to the high incidence of TBIs in South Africa, particularly gunshot-wounds (Bowley & Boffard, 2002). In addition, miners in South Africa have been reported to be at risk for contracting HIV/Aids but studies have shown that they may also be at risk for sustaining a traumatic brain injury given the culture of violence in ethnically segregated single sex hostels (Eisler, 2003). The effect of violence against women in a country such as South Africa cannot be ignored (Goosen et al., 2003; Levin, 2004). Goosen et al. (2003) explain that “in South Africa, women are often viewed as inferior to men, as possessions and in need of being led and controlled, with violence frequently being used to resolve a crisis of male identity” (p. 705). This assumption regarding family roles was echoed in a study conducted by Mokhosi and Grieve (2004). In another study conducted by Jewkes et al. (2002), an estimated 24,6 % of women were subjected to physical violence by a male partner in their lifetime.

Internationally there has been a renewed increase in research related to TBIs sustained in blasts, particularly military servicemen in Iraq and Afghanistan (Galarneau, 2008; Langlois et al., 2006). Belanger et al. (2010) state that traumatic brain injury has been called the “signature injury” of the Iraq war. In addition, rescue personnel and victims of terror-related attacks worldwide are at risk for sustaining a traumatic brain injury (Mallonee et al., 1996).

1.4.2. Cerebrovascular accidents (CVA)

Cerebrovascular accidents (CVA) or stroke involve the interruption of blood flow to the brain. This may occur when a blood vessel or artery is blocked by a blood clot or when blood flow to a portion of the brain is interrupted by the rupture of a cerebral artery (LaPointe et al., 2010). This interruption in blood flow causes damage to the area of the brain robbed of oxygen and may result in significant physical and communication difficulties for the stroke survivor. Similarly, cerebral tumours and infections, including cerebral abscesses, may result in similar difficulties dependent on the site of lesion of the pathology.

1.4.3. Neurological disorders and other pathologies

Policy makers have often been criticised by advocates of neurological disorders such as stroke and TBIs because of their apparent dismissal of the impact of such medical conditions in favour of increased attention on the HIV epidemic in South Africa. This may be due to the sheer magnitude of the epidemic. The Treatment Action Campaign reported that approximately 5.6 million South Africans were infected with HIV by

2008. Bryer (2009) explains that “consequently, other diseases (particularly those relating to lifestyle) have neither received the same attention nor been considered a priority in terms of health expenditure in most provinces” (p. 574). Many studies, however, have indicated that neurological disorders requiring rehabilitation co-exist with HIV/Aids. In the study by Rivara, Grossman and Cummings (1997), household-crowding and poverty were identified as risks for pedestrian accidents. It is interesting to note that these two factors have also been attributed to higher risks of HIV/Aids transmission thereby suggesting a possible co-occurrence of traumatic brain injury and HIV/Aids (Jaffe et al., 2000).

In addition, studies have suggested a link between cerebral infarction in young patients and an increased risk of stroke (Ovbiagele & Nath, 2011; Qureshi, et al., 1997). Bhagwanjee et al. (1997) explain that “HIV-positive patients suffer more septic complications, have a prolonged stay in all phases of hospital care, but the same rates of survival result for injured patients” (Bhagwanjee et al., 1997, as cited by Goosen, et al., 2003, p. 707). Increased risk of stroke has been linked to HIV infections (Cole et al., 2004; Hoffman, 2000 & Mochan, et al., 2003) and the consequences of stroke and need for appropriate rehabilitation is significantly adding to the already stressed burden of disease facing South Africa’s healthcare system (Connor & Bryer, 2005). Bryer (2009) explains that “most patients survive the first stroke, and half are disabled, adding to the financial burden on the health care system and the families who care for them” (p. 574).

Studies have suggested that traumatic brain injury may lead to an increased risk for other health conditions, including epilepsy, depression, hydrocephalus and dementia

(Langlois et al., 2006). In addition, traumatic brain injury has been linked to an increase in reported binge drinking which may place brain injury survivors at risk for alcohol-related dementia as well as additional head and body injuries (Horner et al., 2005).

1.5. The sequelae of a neurological event

Researchers in the field of neurological pathology acknowledge that neurological events such as TBIs, strokes, cerebral tumours and cerebral abscesses may result in significant physical, communication and behavioural difficulties for the injured individual (LaPointe, 2010; Ponsford, 2011). These difficulties may further result in marked limitations in the person's ability to participate in activities of daily living. This may in turn negatively affect the neurologically impaired person's independence and may result in the need for a caregiver.

These physical, cognitive and communicative changes are common after neurological incidents and have been widely reported in the literature (Ergh et al., 2002; Lezak, 1988). In addition, the sudden onset of these difficulties may be overwhelming for family members (Laroi, 2001; Stewart & Reidel, 2011; Wallengren et al., 2008). Due to the sudden onset of these difficulties, family members are not afforded time to adapt to these changes, as for example in the case of a degenerative disease and this can often lead to frustration for both the injured individual and the family members.

1.5.1. Physical sequelae

Most often the physical difficulties that result from a neurological event may be the most obvious sign that something is wrong with the person and may initially prompt the need for medical intervention. Bowley and Boffard (2002) reported that common physical injuries noted in South African road traffic accidents included injuries involving the spinal cord, vascular systems, diaphragm, trachea and pelvis. Extremity injuries and blunt cardiac injuries were also noted as being frequently observed in persons involved in road traffic accidents. In addition, skull fractures and damage to the middle ear ossicles are also common after road traffic accident (Thomsen, 1984).

Physical difficulties commonly identified after a neurological event include motor weakness and inco-ordination, loss of fine and gross motor control, ataxia, reduced physical endurance as well as balance difficulties (Ponsford, 2011). In addition, the neurologically impaired person may present with sensory impairments such as visual loss, hearing loss, tactile impairments and difficulties related to smell and taste (Ponsford, 2011).

When considering specifically road traffic accidents involving children, Winston et al. (2002) explain that the focus of treatment at the scene of an accident is on the physical status of the child. Parents may often bear witness to resuscitation measures as well as other invasive medical and surgical treatments on site and this may add to the psychological distress experienced by the parent. It is suggested by these authors that supportive counselling for the parent caregiver should be offered in such cases due to the traumatic reactions that may result from such an experience.

1.5.2. Communication difficulties

Many different neurological aetiologies may result in cognitive-communicative difficulties. As discussed earlier, these may include TBIs, cerebrovascular accidents as well as dementia and degenerative diseases such as amyotrophic lateral sclerosis. The cognitive-communicative difficulties associated with brain injuries, strokes and degenerative diseases are well-documented (Hartley, 1995; Hartley & Griffith, 1989; Hopper & Bayles, 2008; Myers & Blake, 2008; Peach 2008; Stewart & Riedel, 2011; Wambaugh & Shuster, 2008; Ylvisaker, Szekeres & Feeney, 2008). Ponsford (2011) explains that the communication difficulties commonly associated with TBIs include dysarthria, imprecise articulation and difficulties related to phonation, resonance and prosody during speech tasks. LaPointe et al. (2010) explain that aphasia or a loss of the ability to understand or use language effectively may result from a stroke, brain injury, brain tumour or cerebral infections. In addition, word finding difficulties, receptive language difficulties, expressive language difficulties as well as impaired auditory processing skills may be noted following a neurological event.

The negative impact that these difficulties have on social interaction have also been researched and studied extensively (Anderson, Parmenter & Mok, 2002; Lippert-Gruner et al., 2006; Powell & Wood, 2001). Davidson et al. (2008) explain that “for the person with aphasia changes in language processing immediately impact on his or her daily communication and change the nature of communicative exchanges and the quality of interactions” (p. 325).

Studies have shown that parents consider communication between themselves and their children as vital in building and sustaining the parent-child relationship across the age continuum – “Communication is everything I think” (Marshall & Goldbart, 2008, p.77). As stated earlier, communication difficulties are common after neurological events such as TBIs and strokes. Due to the link between relationship-building and maintenance and communication, these communication difficulties may have a negative effect on the parent-child relationship and may result in frustration.

The process of decision-making and joint discussions surrounding problem-solving within the family may be negatively influenced by the presence of a communication difficulty such as aphasia (Shanmugham, Cano, Elliot & Davis, 2009). It was noted that difficulties with problem-solving within the family were directly related to depression identified in caregivers (Shanmugham et al., 2009). Saban and Hogan (2012) investigated the experience of female caregivers of stroke survivors and noted that communication difficulties were identified as having profoundly negative effects on marital relationships – “my husband’s stroke has been devastating for my family. Our lives will never be the same... his apraxia and cognitive deficits are very difficult to overcome” (Saban & Hogan, 2012, p. 4). In addition, wives reported that the decision-making process very often no longer involved the person with aphasia (Saban & Hogan, 2012). This may be suggested to place additional stress and responsibility on an already overwhelmed partner.

1.5.3. Personality and behavioural changes

Studies have investigated the cognitive symptoms associated with TBIs. These include difficulties related to attention, memory, executive functions and behavioural regulation (Gyurak et al., 2009; Ponsford, 2011). Research has suggested that damage sustained to the frontal lobe of the brain, commonly seen in road traffic accidents, can result in impairments in planning, problem-solving, formulating and evaluating solutions and organisation (Ponsford, 2011). In addition, the ability to monitor and modify one's behaviour has been noted to be impaired following a brain injury (Gyurak et al., 2009). This ability to self-monitor one's behaviour as well as one's verbal output may be negatively affected by an inability to identify errors or negative behaviours. Because a person may be unable to identify negative behaviours or errors in verbal output, he or she may show an inability to correct or modify the behaviour or output. This has been shown to have negative effects on conversational participation, learning new tasks and regulating emotional responses (Gyurak et al., 2009).

A study conducted by Marsh et al. (1998) suggested that behavioural problems demonstrated by persons who had suffered TBIs were more likely to have a severely negative impact on their caregivers as well as on family functioning (Ergh et al., 2002). These difficulties were related to sudden changes in mood, emotional control, aggression and argumentativeness.

Personality changes often exist together with cognitive-communicative difficulties and these often result in difficulties within relationships between family members. In the

study conducted by Saban and Hogan (2012), the injured family members' expressions of negative emotions such as impatience, frustration and anger were noted to result in the caregiver feeling overwhelmed and unappreciated – “all I do (for) my husband and he doesn't say thank you unless I prompt him to. That hurts most of the time.... Feeling much unappreciated. Brain-injured patients aren't always nice and rarely say thanks” (p. 4).

It is important to consider the individualistic impact that the physical, behavioural and communication difficulties have on both the person with the neurogenic communication disorder and the family. Frequently the sudden onset of the difficulties may be overwhelming for family members (Laroi, 2003; Stewart & Riedel, 2011; Wallengren et al., 2008). Because of the sudden nature of the onset of the communication disorders and subsequent changes in physical status, behaviour and communication patterns, family members are not afforded time to adapt to these changes (Laroi, 2003).

1.6. Issues of funding, policy and access

If you are too smart to pay the doctor, you had better be too smart to get ill.

African Proverb

1.6.1. The socio-economic climate of South Africa

When discussing access to healthcare services in South Africa, one cannot ignore the socio-economic climate that pervades this country. Statistics have suggested that approximately half the population of South Africa is unemployed (Statistics South

Africa, 2012). These figures do not include the thousands of illegal immigrants that annually enter South Africa and very often add to the unemployment figures. Many South Africans, although not permanently employed, may gain some income from temporary jobs – often known as “piece work”. In addition, citizens of South Africa have access to limited state welfare funding (Levin, 2004). The small financial contributions received from the state very often are insufficient. Levin (2004) further states that many South Africans are unable to access these grants because they are physically unable to collect their grants due to transport and distance. Furthermore, administrative issues, ignorance and attitude variables may be suggested to further prohibit families from accessing the appropriate grants (Anderson, 2002).

1.6.2. Access to acute medical care

A study undertaken by Van Der Spuy and Steenkamp (1996) showed that appropriately 47.6 % of patients presenting with injuries or acute illness such as cerebrovascular accidents arrive at hospitals by private vehicles – very often after having to wait a long time for transport to be arranged. It is my experience that the individuals offering transport to and from hospitals and primary healthcare clinics, very often charge exorbitant fees for their services thereby limiting the number of patients able to make use of such services. In addition, Levin (2004) points out that many children are transported to hospital in taxis without the mandatory use of seatbelts and child protective seating, thereby placing them at risk for a traumatic brain injury if involved in a taxi accident. Levin (2004) in her investigation noted that children up to the age of four years are very often transported on an adult’s lap in order to avoid paying for an additional seat.

Another factor exacerbated by the lack of efficient transport services in the case of an emergency, is the “golden hour” - “pre-hospital time longer than one hour impacts negatively on survival in hospital, possibly due to prolonged hypoxia/hypo-perfusion” (Sampalis et al., 1993, as cited by Goosen et al., 2003, p. 705). It has been estimated that the average time taken for a patient to reach the hospital is 120 minutes (Goosen, et al., 2003) – double the maximum “golden hour”. Failure to attain appropriate medical treatment within this time frame may negatively affect the patient’s potential for recovery and may result in a poorer prognosis.

When discussing issues relating to access to appropriate healthcare services, funding is probably the most pertinent yet controversial issue related to access. Goosen et al. (2003) explain that “because of a lack of affordability, limitations have to be placed on active treatment of certain injuries, e.g. gunshot-wound of the brain crossing the midline, and certain admissions to intensive care” (p. 707). This was also noted in a study conducted by Van Der Spuy and Steenkamp (1996).

Availability of beds in training hospitals remains problematic and may often result in patients being discharged or referred to smaller hospitals even though this may not be in the best interest of the patient concerned (Goosen, et al., 2003). In addition, shortages of appropriate skilled specialists are a common factor in government hospitals, although posts for these specialities are available (Goosen, et al., 2003). This may also be due to the fact that remuneration in the public sector is significantly less than in the private sector – this trend is noted across all disciplines including rehabilitation. Very often the services offered by public health institutions are inconsistent and are affected by

high staff-turnovers. Wales (2002 as cited by Levin, 2004) found that many experienced healthcare professionals accept higher paid positions in the private sector and, because of this, the services available in the public sector are often offered by inexperienced healthcare professionals.

Appropriate and up-to-date medical equipment shortages are also a common problem in the public healthcare system. These shortages highlight the disparity between the resources available in the public versus private healthcare settings. Goosen et al. (2003) explain that “public funding for tertiary care (intensive care, CT, MRI) is still severely prescribed, whereas the number of private CT- and MRI-scanners in one province (Gauteng) at one stage exceeded those in the whole of Britain” (p. 706). This suggests an unequal distribution of sufficient and appropriate medical equipment as opposed to an absence of such equipment.

1.6.3. Access to private medical funds

Surveys have suggested that approximately 18 to 20 % of South Africa’s population have access to private medical funds (Goosen et al., 2003; Levin, 2004). These private medical funds are most often subsidised by employers and are, by default, then only accessible to people who remain in the employment of the company. The majority of South Africans make use of too often limited and under-resourced public healthcare facilities.

1.6.4. The effects of urbanisation

When discussing the state of healthcare in South Africa, one cannot ignore the effects of urbanisation – a key characteristic of the developing world and countries such as South Africa. Goosen et al. (2003) explain that the growth of cities and the migration of individuals from rural areas to urban areas results in “mass unemployment, lack of adequate shelter and basic infrastructure. When combined with weak social services and obvious disparities between the ‘haves’ and ‘have-nots’, it results in a high degree of social exclusion leading to overall social dysfunction, crime and violence” (p. 705). This idea was also highlighted by Fisher and Charlton (2001) in their study examining the increasingly risky behaviour demonstrated by adolescents migrating to more urbanised areas.

This trend of urbanisation has also resulted in the breakdown of the nuclear family, particularly within rural South Africa. Levin (2004) explains that women are very often forced to leave their children in the care of other women in the community, in order pursue job opportunities away from home. However, if the women and children reside in urban areas, “these single mothers do not have the support of other women, which is a hallmark of traditional child-rearing practices, especially in the rural areas” (p. 307). This trend may place the mothers at risk for abusing or neglecting their children due to the lack of support structures and resources available to single mothers in the cities of South Africa (Levin, 2004). In addition, these children are placed at greater risk for sexual abuse, gang activities, taxi accidents and car hijackings (Levin, 2004). In addition, Levin (2004) proposes that a link between child rape and TBI, particularly due to the violent nature of the rape, cannot be ignored.

1.7. The Reality of Rehabilitation of Adult Neurogenic Disorders in South Africa

Rehabilitation following neurological fallout is a complex field. Rehabilitation in a developing country such as South Africa may be described as challenging, not only in terms of the severity of the conditions and resulting disabilities but also because of various factors associated with the South African milieu. Balancing the need for rehabilitation with the practical considerations that facilitate rehabilitation is tricky to say the least.

Rehabilitation of patients no longer requiring acute medical care remains problematic in South Africa. Goosen et al. (2003) estimate that between “25 to 30 % of our acute care beds (are) blocked at any one stage by patients awaiting transfer to rehabilitation facilities” (p. 707). These authors further state that “the private sector shows the exact converse, with excellent acute facilities and chronic facilities abounding” (p. 707) – an idea that may not be factual. There are only three dedicated private rehabilitation units in Gauteng (Life New Kensington Clinic, Life Riverfield Lodge and Netcare Auckland Park Rehabilitation Hospital) and few private therapy practices are adequately equipped to manage neurologically impaired patients in Gauteng. This may be due to the expense associated with setting up such practices and the acquisition of equipment and therapy resources, including personnel, necessary to appropriately manage persons with neurological damage once they are discharged from hospital.

Not all medical aids may cover inpatient rehabilitation and those that do require formal applications and supporting motivational documentation to secure authorisation for

funding of physical rehabilitation services. Even though patients may have access to funding from the medical aids for rehabilitation, they may not have access to the services offered by the private sector. This may be due to the lack of appropriate services, transport and inexperience of clinicians. This is particularly evident when investigating the rehabilitation services offered to children who have sustained TBIs. Levin (2004) states that “even in the wealthiest sections of the population, services for children with TBI are insufficient” (p. 306). She further states that “the rehabilitation literature on paediatric TBI assumes that children have opportunity for top-level medical care in the acute stage, followed by a transition period in a regular paediatric ward, support through the transition to home-based care, and access to rehabilitation” (p. 308). This is, however, definitely not the case for adults or children who have sustained TBIs. In addition, very few patients who have suffered aneurysms and cerebrovascular accidents are afforded these services in South Africa.

Even though appropriate rehabilitation services may exist in urban areas in South Africa, these are very often not accessible to South Africans living in rural areas (Bryer, 2009). It is estimated that approximately half of the South African population currently reside in rural areas (Department of Environmental Affairs and Tourism, 2003). For this reason, time and distance have been identified as factors that limit the availability of appropriate healthcare services to all South Africans, a phenomenon seen in many developing countries (Bryer, 2009; London et al., 2001). In addition, transport services to appropriate hospitals and clinics is lacking and very often challenging (Goosen, et al., 2003; Levin, 2004). This results in many patients being unable to receive appropriate rehabilitation intervention.

Having worked in the private sector, I have become aware that medical aid authorisations and funding for treatment are by no means sufficient to ensure that patients with private medical funding receive appropriate rehabilitation. Many patients, who have medical aids due to employer subsidies, may not have the financial resources to access rehabilitation. As stated earlier, private transport to medical facilities is often very costly and unreliable for patients who do not have their own means of transport. Very often these patients are vulnerable to being exploited by members of the community looking to gain financially from their desperation to receive rehabilitation.

Medical aids offer very limited cover for rehabilitation following discharge from inpatient facilities (Doherty and McLeod, 2002; McIntyre et al., 2012). In addition, even if limited cover is offered, medical aid funds are frequently exhausted before therapy aims have been achieved. Patients may be able to access private rehabilitation for a period of time, but once their medical aids are depleted, rehabilitation stops. In my experience, I have noted that very few private practices are willing to negotiate reduced rates for therapy as these patients would fill up appointment slots that could be occupied by medical aid funded or “paying” patients. In addition, because poverty can also affect those with medical aids, few patients are able to privately fund rehabilitation once their medical aid funds have been exhausted. This may be due to the fact that “the majority of adults within the formal employment sector earn minimal wages, which do not allow them to pay for private medical care” (Levin, 2004, p. 308).

A trend of “cash only” practices has been noted in the past years whereby patients are required to initially pay for therapy services and then claim back from their medical

aids. Again, in my experience, only a limited number of patients requiring rehabilitation are able to “pay now, claim later”. This may also be due to the fact that many of the patients accessing rehabilitation for neurological conditions, such as TBIs and strokes, are unable to return to work, either temporarily or permanently and therefore, many must accommodate a loss in earnings and benefits, such as travel allowances and overtime wages. Very few adults are able to contribute to private medical aids without the financial assistance of their employers (Levin, 2004).

Acquiring the funding for the appointment may only be part of the problem for the patient. In addition, caregivers may need to apply for a day’s leave in order to accompany the patient to an appointment. This may result in a loss of income for the day or may, in the longer term, jeopardise their jobs. The effort, financial cost and logistics of getting the patient to the therapy appointment may outweigh the perceived benefit of the therapy appointment. It is for this reason that caregiver training and the implementation of home programmes is vital to facilitate the best possible prognosis for the patient (Bryer, 2009). In addition, the need for easily accessible community-based programmes for patients who have suffered neurological fallout is obvious (Bryer, 2009).

Such community-based programmes may include support groups. Support groups for persons who have suffered neurologically debilitating events and diseases are available in South Africa. These groups are, however, frequently located in urban areas and are not accessible to patients in outlying rural areas of South Africa. Furthermore, the information provided by such groups is often made available on the internet and few

families in rural areas may have access to such facilities and may, therefore, not be able to make use of such support and information services.

As evident in this chapter, there are many challenges facing therapists involved in the rehabilitation of adults and children who have suffered neurological events such as TBIs and strokes. These challenges although great are not impossible given the resilience, passion and determination shown by many health professionals working within the South African context, both in the public and private sectors. Levin (2004) suggests that “a re-focus on the strengths of existing structures and the creation of new possibilities is suggested as a positive and constructive approach to prevention, rehabilitation and education” (p. 306). Appropriate training of healthcare professionals in the rehabilitation field is vital (Bryer, 2009). In addition, professional development and peer support is necessary to aid clinicians in both the public and private sectors. In South Africa, community service for healthcare professionals was made mandatory in 2001. This allowed for the development of rehabilitation services in facilities that were unable to offer such services in the past. Because of staff shortages in government facilities, however, inexperienced therapists are very often placed in positions in which they may be the sole therapist providing rehabilitation services and may not have the benefit of working with a more experienced therapist.

1.8. The timing of rehabilitation

It is well documented that the most significant recovery, including physical, speech and cognitive functions, occurs within the first six months following the neurological event

(Dobkin and Carmichael, 2005; Fawcett et al., 2001; Ponsford, 2011). It is, therefore, suggested that although recovery from a neurological event may continue for years following the event, the physical, speech and cognitive functions may be stable after a period of two years (Cramer, 2008). Ponsford (2011) states that recovery following a traumatic brain injury resembles a negatively accelerating curve with the most significant recovery evident within the first three to six months following the event. In addition, the degree, course and recovery pattern is difficult to predict as many factors are suggested to influence the recovery process (Ponsford, 2011). These include the injured person's premorbid personality characteristics and learning style, previous history of brain trauma, the nature and severity of the injury as well as the location and extent of the brain damage (Belanger et al., 2010; Ponsford, 2011). Falk-Kessler (2011) states that "although the initial recovery phase may be marked by some improvement in one's physical status, a plateau period during which progress is slowed often follows and may lead to frustration and sadness" (p. 51). This may be suggested to negatively impact on the caregivers' experiences of caring for their neurologically impaired adult child.

Lezak (1986) states that this sudden change and inadequate adaptation to the changes in the family may result in increased family strain. In addition, this may also result in a range of emotions from denial to depression, particularly in the first few weeks – "the grieving stage is the initial impact of a condition, whether it be stroke or death, but then almost when the dust settles all of a sudden depression sets in ... and it's a good subject to talk about – grieving and depression" (Fox et al., 2004, p. 1196). In my experience, I have observed that very few families and patients understand and believe that the communication difficulties may be long-lasting and many wait for either they or their

family member to “wake up” fully healed and as they were before the incident. This may be suggested to affect their motivation to participate in therapy in the initial stages. In addition, conflict may arise in families when members have different reactions to the communication-disabling event, prognosis and the rehabilitation plan. The “circle of conflict” may further be widened to include medical professionals such as therapists, who have differing ideas and expectations of the recovery process.

CHAPTER TWO

2.1. The needs and experiences of caregivers.

There are only four kinds of people in the world -

1. Those who have been caregivers
2. Those who currently are caregivers
3. Those who will be caregivers,
4. And those who will need caregivers.

Rosalynn Carter (1987)

The above quote by Rosalynn Carter describes the growing trend of people requiring caregivers and those taking up the responsibility of caring for their loved ones. In South Africa, this may be due to the increase in both communicable, for example HIV/AIDS, and non-communicable diseases such as stroke and TBIs. In addition, studies have shown that the number of adult children requiring care from ageing parents is on the increase (Rizzolo et al., 2009; Weeks et al., 2009). Due to an increase in life expectancy of both the parent caregiver and the impaired adult child along with the trend of de-institutionalisation, researchers are focusing more interest on the experiences of older adults resuming the care of their adult child in later life (Corsentino et al., 2008; Yoong and Koritsas, 2012). These studies have largely focused on intellectual impairments and psychiatric disorders. There appears to be a dearth of literature describing the experiences of older parents caring for the neurologically impaired adult children.

2.1.1. From loved one to caregiver

Very often it becomes the responsibility of the injured person's family member to provide care, assistance and to supply the financial needs and resources required by the injured person. The family's feelings of anxiety, distress and even depression may increase as they attempt to meet the various needs of the individual (Hartley, 1995; Natterlund, 2010). These needs may include long-term financial and daily living needs as well as social and recreational needs.

In addition, in the presence of cognitive-communicative difficulties the job of caregiver may be seen to become more difficult as these difficulties may impinge on the relationship between the caregiver and the care recipient. Studies have shown that the relationships most affected by neurogenic communication difficulties are the ones between the injured individual and immediate family members (Anderson et al., 2002; Boschen et al., 2007 & Natterlund, 2010). This may be due to the increase in demand placed on the family member as caregiver as well as conversational partner.

The focus of rehabilitation following a neurological event or diagnosis is very often on the individual presenting with the communication disorder (Lutz and Young, 2010; Threats, 2010). Threats (2010) states that the needs of the family are seldom adequately addressed and frequently interactions between therapists and family members involve providing information and reviewing home therapy programmes. Laroi (2003) suggests that the therapy required by families who have been affected by brain injuries "is distinct from family education and support in that it involves working toward actual

change in the family's organisation, structure or communication patterns" (p. 176). Because of the resultant cognitive-communicative difficulties identified following stroke and brain injury, family dynamics are more often than not affected (Bowen et al., 2009). Because of these changes in family dynamics – changing roles, family members' feelings of loss and uncertainty, the family caregivers' quality of life may be compromised as a result of the communication difficulties (Natterlund, 2010; Glozman, 2004; Savundranayagam, et al., 2005 & Wallengren et al., 2008). Hartley (1995) explains that families of individuals who have suffered TBIs faces challenges in coping with the changes in their injured family member as well as the changes in the family itself. Difficulties in accessing healthcare services in South Africa such as those discussed earlier further add to the family's distress.

2.1.2. Role changes in the family following a neurological event

Roles changes within the family are common following a neurological event such as a brain injury or stroke (Natterlund, 2010; Wallengren et al., 2008). Family therapists suggest that it is vital for the therapist involved with families who have been affected by brain injuries to gain an understanding of the pre-injury roles including the distribution of power and authority (Laroi, 2003). Laroi (2003) explains that the consequences of the roles changes evident after a brain injury may result in either a re-establishment of roles as they existed before the injury or may necessitate redistribution of roles following the injury due to the injured individual's inability to fulfil his or her pre-injury role in the family. Laroi (2003) further explains that these role changes may specifically affect the parent-child relationship, particularly when the brain injury results in an increased dependency of the parent on the child. Children may need to

assume the roles of the parent's caregiver and this would result in a significant change in the communication patterns of the family (Laroi, 2003).

2.2. Old and Vulnerable Looking After Young and Vulnerable – Parenting the Third Generation

“I don't have any problem because I am supporting my own blood”

Dorah (Schatz, 2007).

2.2.1. Grandparents reparenting grandchildren

Increasingly older members of communities, such as grandparents, are assuming the responsibility of caring for younger members of the community due to the illness or death of the younger members' biological parents. Reasons for this include the high mortality rate of young adults particularly due to the HIV / AIDS epidemic. It was estimated by the United Nations that in 2009 approximately 10.6 % of the general population of South Africa would have been diagnosed as HIV positive (UNAIDS, 2009). Much attention has been given to grandmothers needing to raise grandchildren in South Africa particularly due to the AIDS epidemic (Bohman, Van Wyk and Ekman 2009; Poindexter, 2007; Schatz, 2007; Van Dyk, 2001). Other factors contributing to this trend include migration, unemployment as well as a high rate of non-marital births (Schatz, 2007). This notion of the grandmother being actively involved in her grandchildren's lives is, however, not new. Bohman et al. (2009) explain that “the aged grew up with grannies that took care of them as well as educated them through storytelling and they perceive themselves as transferors of tradition” (p. 451).

This is in sharp contrast to a country such as Canada in which approximately only two grandchildren in one thousand reside under the care of their grandparents (Milan and Hamm, 2003 in Olazabal, 2010). Shatz (2007) explains that “these elderly women, who as a collective would usually be considered a ‘vulnerable population’, are themselves taking care of other vulnerable household members – ill adult children, and fostered and orphaned grandchildren” (p. 153). In addition, it has been identified that the grandmother placed in the parental role may not be biologically related to the children in her care (Schatz, 2007). Other female family members, such as aunts, sisters and other female community members have also been called on to be involved in the raising of children orphaned by HIV/AIDS (Freeman and Nkomo, 2006; Gwebu 2008).

Not only have grandmothers taken on parental responsibilities, so too have grandfathers needed to change their idea of male role models encouraging the development of a more involved grandfather (Mann and Leeson, 2010, Patrick and Tomczewski, 2007). In addition, in a study conducted by Bailey, Letiecq and Porterfield (2009) it was found that grandfathers perceived their involvement in the raising of the grandchildren as a second chance at parenting. This was perceived by the grandfathers as having a positive effect on bonding and socialisation with their grandchildren (Bailey, et al., 2009). Very little research has been done regarding the role of the grandfather in the South African milieu and investigations into the experiences of both grandfathers and grandmothers actively raising children in this context is needed.

2.2.2. The benefits of intergenerational contact

Studies such as the one conducted by Schatz (2007) highlight the growing trend of intergenerational families in South Africa. For the purposes of this study, an intergenerational family will refer to a family in which more than one generation resides in the same home. With this in mind, however, it is strongly suggested that this trend allows for and enforces a significant amount of intergenerational contact and communication. Bohman, Van Wyk and Ekman (2009) found that participants in their study frequently came from three generational households that were headed by a matriarch. In addition, because of the growing HIV / AIDS epidemic as well as a growing population of older people and increasing life expectancies, it is suggested that the need and enforcement of intergenerational contacts will increase (Pinazo-Hernandis and Tompkins, 2010; Poindexter, 2007). Poindexter (2007) states that “while parenting grandparents experience the usual challenges of parenting, they also have added stresses of their own developmental, financial, and health concerns as well as special needs of children who have lost a parent” (p. 78). Studies have shown that levels of education and accessibility to economic and social resources were very low in these intergenerational families (Fuentes, Bernedo and Fernandez-Molina, 2007; Gwebu, 2008) and grandparent caregivers experience significant challenges even though they are committed to their role as caregiver (Conway et al., 2010). Very often the pensions provided by state programmes are insufficient to finance these growing families (Bohman et al., 2009; Gwebu, 2008; Schatz, 2007). Poverty may be seen to further stress an already stressed system and the introduction of the child support grant in 2008 has done little to ease the financial burden commonly associated with intergenerational households (Moller, 2010).

These grandparents, however, reportedly viewed the decision to raise their grandchildren as positive and saw it as an opportunity for them to remain active, build relationships with their grandchildren while enjoying the companionship of others during their later years (Poindexter, 2007). This finding appears to be seen in other countries and not only within the South African context (Fuentes, et al., 2007; Winston, 2006). Care professionals, however, cannot ignore that activities such as support groups and religious service attendance improve the grandmothers' experience of caregiving (Park, 2009). Anecdotal evidence suggests that in the South African context, grandmothers' involvement particularly in religious activities is common.

The focus of this study is the experiences of parents who have had to resume the caregiving needs of their adult children due to a neurological event. This is suggested to be in contrast to what is the accepted norm in countries like South Africa. It may be suggested that many older parents expect to be cared for by their children, particularly if the children are employed (Schatz, 2007). Gwebu (2008) explains that the role of the older male child in Botswana typically involves the care of ageing parents. He states, however, that "the intergenerational contract through which parents would be assured of support from their children during their twilight years is rapidly being threatened by the HIV/AIDS pandemic" (Gwebu, 2008, p. 427). Gwebu (2008) cautions that, particularly in the African context, younger children have been called upon to care for and support older members of their family and the wider community. These children, and very often even adult caregivers, are frequently ill-equipped and emotionally inept to adequately fulfil this role (Gwebu, 2008; Orner, 2006).

In sharp contrast, adults in countries such as Canada are seen as not as willing to care for their ageing parents as they are unprepared to make the necessary sacrifices, such as resigning from work, to become caregivers (Olazabal, 2010). In Canada and some Northern European countries, it is noted that adult children demand and expect that the government assist with the care of their ageing parents (Olazabal, 2010). Once confronted with their own frailty and need for assistance to accomplish activities of daily living, these individuals may employ professionals to assist them rather than approaching their children for help (Olazabal, 2010).

2.2.3. The need for research into the effects of cognitive-communicative difficulties on intergenerational families

In a comprehensive literature review citing studies related to the effects of acquired brain injuries on families, Boschen et al. (2007) state that early research into this field primarily focused on the parents of children with brain injuries. According to these authors, research interest then changed to include spouses and children of brain injury survivors (Boschen, et al., 2007). Research into the effects of cognitive-communicative difficulties on intergenerational families such as in the South African context is, however, lacking. In addition, the ways in which different cultures in South Africa perceive the effects of neurogenic communication disorders in family systems also requires further investigation. Such investigations would facilitate the development of culturally appropriate therapy programmes for neurogenic communication difficulties – approaches that are lacking in South Africa at present (Wasserman et al., 2009). These pose interesting research topics for speech and language therapists in South Africa today.

2.3. Family Systems Theory

When discussing different and changing family structures, it is useful to consider the theory of family systems. Family Systems Theory (FST) is a theoretical and therapeutic orientation that has its origins in Kelly's Systems Theory (Becvar and Becvar, 2009). This systemic framework has, however, evolved significantly in the last 60 years to find applicability in a wide variety of settings.

At its heart, FST sees the individual as existing within the context of an ever-expanding set of relationship matrices or systems (Becvar & Becvar, 2009). Within this context, the individual is never seen as existing outside the context of the system (Becvar & Becvar, 2009; Maitz & Sachs 1995). Instead, the individual is seen as affecting and being affected by all other members of the system (Bateson & Donaldson, 1991; Becvar & Becvar, 2009; Keeney, 2002).

In addition, FST embraces concepts from the social constructionist school of thought in order to describe the way in which all rules and boundaries allow the system to be clearly defined and to function effectively (Becvar & Becvar, 2009; Keeney, 2002). Within this framework, all roles and experiences within the family are not only connected, but work in a manner in which all rules and boundaries are co-constructed by the members of the family system (Becvar & Becvar, 2009). Effects within the family system and larger systems to which it is related are therefore far-reaching.

As a result of this wider casting of the net, the move is away from focussing on maladaptive patterns and thus pathologising the individual or “patient”. Rather the focus is on moving towards mobilising healthy and adaptive resources within the world of the system and the individual (Bateson & Donaldson, 1991; Keeney, 2002). The individual is no longer the “problem” rather it is the breakdown of effective functioning in the system as a whole (Maitz & Sachs, 1995). Furthermore, FST, in expanding the clinical focus from that of the individual to that of interconnected systems, allows the therapist greater access to resources within and connected to the family system (Becvar & Becvar, 2009). This may then be used to assist the family system in moving towards greater functionality despite, as in the case of this study, the consequences of the neurological event.

According to FST theorists the system functions well when role allocation and role fulfilment are optimal (Maitz & Sachs, 1995). The adequate performance of these roles is vital for the adaptability of the system as a whole. Should situations change, such as in the case of an illness or neurological event, roles within the system may need to make corresponding changes in order to allow the family system to continue to function effectively (Becvar & Becvar, 2009; Maitz & Sachs, 1995).

The FST framework is of particular use in the treatment of individuals, families and systems in which the problem is acute (Becvar & Becvar, 2009). This is of particular use in the context of the current study in which participants have been faced with the sudden onset of physical, cognitive and communicative difficulties caused by a neurological event.

2.3.1. The Family Systems – Illness Model (FSI Model)

After the occurrence of a neurological event or the diagnosis of an illness, families are placed in a paradoxical position in which they have to maintain focus on the present and the future simultaneously whilst mastering practical and emotional tasks required of their immediate situation, all while charting a course for dealing with the complexities and uncertainties of their problem in an unknown future (Rolland, 1999). This is a daunting task and one, which when considering the need for the system as a whole to operate effectively and with appropriate role allocation, can create difficulty for families trying to accomplish many simultaneous tasks.

Describing and facilitating the accomplishment of this task, both for the family and for the purposes of providing a coherent lens for treating therapists, is perhaps best achieved by placing the unfolding chronic condition in a developmental model of system functioning that integrates three evolutionary threads – the illness, individual life cycles and belief systems (Rolland, 1999) .

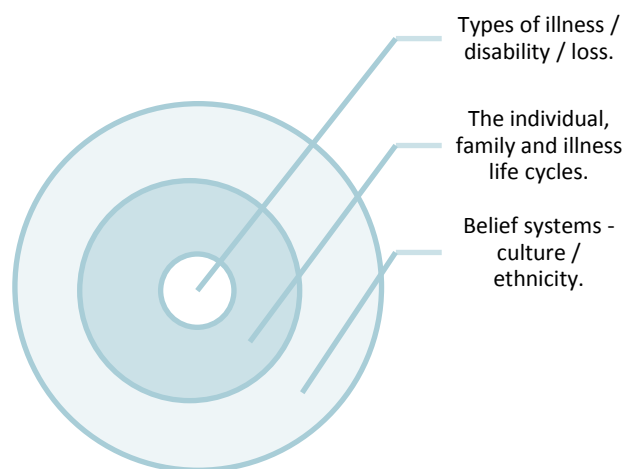


Figure 1: The Family Systems – Illness Model (Rolland, 1999, p. 243)

This Family Systems – Illness Model (FSI Model) is grounded within FST, allowing for a detailed description of the family and individuals’ attempts at adapting and adjusting, all while trying to accomplish tasks that are still developmentally important to both the individuals and the larger system (Rolland, 1999).

While it is important to note that Rolland’s Model is described as being particularly useful in identifying patterns of interaction and change in a model diametrically opposite to that of the present study, that is of a young child’s experience of loss of healthy parent, it was deemed an appropriate vehicle for the current study because of its wide-spread applicability (Bowen et al., 2011; Rolland, 2005; Tramonti et al., 2013).

Rolland (1999) describes a three-stage model of family adjustment to loss and the resultant physical and cognitive-communicative changes as a result of chronic disorders, with particular emphasis on a biopsychosocial orientation with the family as the interactive focal point.

The FSI Model addresses three key dimensions of the changes and adaptations required of families after the occurrence of a disorder or illness: (1) the psychosocial types of illness; (2) developmental phases in the family/ individual/ disorder’s life-cycle; and (3) family system variables such as belief systems (Rolland, 1999).

2.3.1.1. The psychosocial type of illness

Rolland's first stage of family adjustment to illness requires mapping the path that the illness takes, and how the interaction between the interlocking processes of the family, the individual and illness is identified. The psychosocial type of illness refers to the psychosocial demands that the physical illness or disability places on the family system (Rolland, 1999).

According to Rolland, illnesses can be divided into those in which onset is acute, such as strokes or TBIs, or gradual such as in Huntington's Disease or Motor Neuron Disease (MND). For the purposes of this study, it is in the description of the changes in acute onset conditions that Rolland's model is most useful.

In acute onset conditions the affective and practical changes required of families are compressed into a short time. Many authors have acknowledged that families are given very little time to adapt to the changes brought about by a family member's neurological event (Faircloth et al., 2005; Ponsford, 2011). It is the sudden onset of physical, cognitive and communication difficulties that requires the rapid mobilisation of crisis management skills from family members. This is suggested to contribute to severe disruption and alteration of established patterns of family functioning (Rolland, 1999; Verhaeghe et al., 2005).

In cases such as these, the family needs to be helped to tolerate highly charged emotional situations, adopt a more flexible stance towards role changes, develop

effective problem-solving skills and optimise their utilisation of outside resources (Rolland, 1999; Verhaeghe et al., 2005).

Illnesses, according to Rolland (1999), will generally follow one or more of three trajectories. Firstly, progressive conditions, such as Motor Neuron Disease, worsen in step-wise deterioration and cause growing strain and exhaustion amongst families attempting to cope with the illness and its attendant sequelae. Of interest to this study is Rolland's description of constant conditions which are characterised by a sudden initial event which is then followed by a stable biological progression. In these constant conditions there is an initial period of recovery, such as the spontaneous recovery after a neurological incident, but clear-cut deficits or limitations persist. When examining neurological events such as TBIs and strokes, these deficits relate to the physical, communication and cognitive symptoms described in Chapter One. Rolland (1999) explains that families affected by a loved one's neurological event are faced with a semi-permanent change that is stable and predictable over a predictable timespan. The potential for family exhaustion exists without the strain of new role demands over time, as these roles become cemented over time. Finally the relapsing or episodic condition, where the key element is the frequency of the reoccurrence of the illness, gives rise to a dynamic cycle of crisis/ non-crisis.

Rolland (1999) also proposes that the extent, type and timing of disability that results from the illness will affect the degree of family stress experienced. He notes that conditions which encompass combined cognitive and motor deficits, such as those caused by a neurological event, necessitate an even greater family role reallocation and

which correlate strongly, at times, with the changing developmental needs of the family and its members.

2.3.1.2. The lifecycle of the illness, individual and family

The extent to which a chronic illness leads to death or shortens one's life span, has a profound psychosocial impact on the family (Rolland, 2005; Rolland 1999). The family and individual's initial expectation of what the likely progression and outcome of the illness is can lead to a sense of anticipatory loss (Rolland, 1990). In conditions in which the individual's condition is terminal, the family system has to address death as an outcome but this anticipatory loss may still be evident in families where the loss may be described at a physical, cognitive and or communicative level. Frequently, families and individuals are likely to ask: What is the next thing I/we will lose? This may result in significant uncertainty and fear for the family members as they anticipate both recovery and loss simultaneously.

While the diagnosis of an illness may be experienced by the individual or family as a static and sudden moment in time, Rolland (1999) points out that therapists working with families under such conditions need to appreciate the dynamic nature of the recovery process which unfolds over time. Rolland (1999) again uses a three-stage conceptualisation of this process, with each stage requiring particular strengths and skills to navigate.

In the Crisis Phase, which Rolland (1999) perceives as occurring immediately prior to and after diagnosis, family members are frequently faced with grieving the loss of the pre-illness family identity; having to accept the permanency of the illness; and developing short-term crisis reorganisation skills all while developing family flexibility in the face of uncertainty. This phase stands out as the time in which families learn to live with illness-related symptoms and treatments. It is vital, according to Rolland (1999), that a key focus of this phase is the forging of relationships between healthcare professionals and families. This is an idea echoed by Verhaeghe et al. (2005).

Rolland (1999) describes the Chronic Phase as “The Long Haul” in which the stresses of day to day living, pacing and avoiding burnout, possible relationship skews between the patient and other family members, the need for sustaining autonomy by family members, preserving or redefining individual or family developmental goals are now dealt with within the constraints set down by the illness.

Rolland (1999) explains that the final phase is the Terminal Phase in which the idea of death becomes apparent and dominates family life. This phase is not generally applicable within this study. It is applicable, however, in the cases of degenerative neurological conditions such as MND, cancer, HIV/AIDS.

Given the dynamic nature of family systems, it is important to point out that these phases are dynamic and critical transition periods link these time phases (Rolland, 1999). It is during these critical transition periods that families re-evaluate themselves.

Rolland (1999) suggests that it is during these periods that families find creative solutions to problems, seek information from sources and make plans that will facilitate their transition to an easier life. These transition phases are frequently the moment in which shifts in relationships within the family system and larger rehabilitation systems will take place, as therapy or life goals are either adjusted or new ones set (Rolland, 1999).

In addition, Rolland (1999) states that therapists need to be aware of the life stages of both the individual family members and the family system. He points out that the occurrence of a chronic disease, or in this case a neurological event, during a specific phase of the life cycle such as childrearing, may cause significant distress for the family, as individuals and as a system. The further complication of stressed resources, such as finances and time, further adds to the stress experienced by the family system (Rolland, 1999).

2.3.1.3. The family's belief system

Rolland (1999) explains that it is important to investigate and understand the family's unique beliefs regarding the illness or disability. He further proposes that the family face the primary developmental challenge of creating meaning for the illness. This may promote a sense of competency within the family or result in feelings of impotence.

2.4. The effect of communication difficulties on family relationships

Gan and Schuller (2002) and Laroi (2003) state that although many studies have investigated the impact of brain injury on individual family members, little scientific evidence is available with regards to the impact on the family system. They caution that these studies frequently involve interviews with one member of a family and the sentiments expressed by this single member are often said to be representative of the family as a whole. The researchers state that although individual differences may be identified in different family members, the brain injury may have a permanent effect on the entire system. This is a notion postulated by family systems theory (Bowen et al., 2009; Gan et al., 2006; Gan and Schuller, 2002). Therefore, it may be suggested that difficulties experienced by one member of the family may have a ripple effect on the family as a whole. Conversely it may be suggested that any positive change brought about in one family member's experience by appropriate intervention may then affect the family system. Gan and Schuller (2002) explain that in family systems theory the focus shifts from the "injured individual" to the "injured family" – an idea also suggested by Lezak (1986) and Evans (1994).

Studies suggest that the needs of the spouses of individuals who have suffered brain injuries and strokes are long-term (Anderson et al., 2002; Le Dorze & Signori, 2010; Natterlund, 2010). These needs arise from the changes in the couple's relationship, particularly due to changes in communication patterns, roles and responsibilities within the family (Le Dorze & Brassard, 1995). Studies have shown that "clear and accurate communication between spouses is considered essential in maintaining relationships and is an expected element in marital roles" (Beach & Arias, 1983 and Kahn, 1970 as

cited by Joubert et al., 2010, p. 35). Hence a change in communication efficiency, such as dysarthria or aphasia, may be suggested to have a significant effect on the relationship and marital roles. Furthermore, Threats (2010) suggests that the spouse of the impaired individual can be viewed as the “hidden victim” and may be the most important and / or willing communication partner. This idea is echoed in the study conducted by Wallengren et al. (2008).

A South African study conducted by Joubert, Bornman and Alant (2011) investigated speech intelligibility and marital communication in amyotrophic lateral sclerosis. This study suggested that the rapid decline of speech intelligibility markedly affected marital communication and that this deterioration in communication further affected the couple’s perception of their marital relationship. A study conducted by Ball, Beukelman and Pattee (2004) suggested that education regarding appropriate compensatory strategies to maximise speech intelligibility in social situations for people with amyotrophic lateral sclerosis is necessary in order to minimise communication and improve interactions. It may be suggested that improved intelligibility may improve the quality of interactions and ultimately have a positive effect on interpersonal relationships.

One cannot ignore the unique communication patterns and relationships in the family that were established before the neurological event or disease and that premorbid factors such as personality styles and ways of dealing with conflict and stress would continue to influence family dynamics (Laroi, 2003; Threats, 2007). Threats (2010) acknowledges that communication problems in marriage relationships are frequently reported in

marriage counselling sessions even when the individuals concerned do not present with neurogenic communication difficulties. It is vital that rehabilitation therapists “identify protective or resilience factors that the family already possess, and to acknowledge and connote their positive role to families to ensure that they utilise and benefit from these as much as possible” (Taylor, Fuggle & Charman, 2001, p. 961).

A study conducted by Sedgwick and Watt (2000) examined adolescents’ perceptions of their quality of life following a caregiver’s traumatic brain injury. This study suggested that the adolescents interviewed perceived their quality of life as negatively affected by the traumatic brain injury. As normal adolescent development is characterised by rapid physical changes coupled with changes in cognitive processing it may be suggested that when extra stress is placed on families, these changes may often be exacerbated (Allison, 2000).

In addition, negotiation between parents and adolescents is vital during the teen years. It is during this time that both parents and adolescents attempt to modify their relationship dynamics through negotiation and communication (Allison, 2000). A person with a communication disorder may not be able to negotiate with a child in the same way as the uninjured parent because of cognitive-communication difficulties. This inability to effectively communicate may have a negative effect on the parent-adolescent relationship. This was noted in the study conducted by Sedgwick and Watt (2000).

In addition, the reduced amount of interaction between the parent and the adolescent in this study were highlighted as negatively affecting the adolescent's quality of life - "he doesn't want to talk a lot anymore and stuff. I don't know. It looks like he's scared or something... we would always make supper together – throw in a lot of spices, make jokes and stuff like that. That's how it used to be. And now he just gets me a potato and he goes and sits down while I make supper. And not really offer to help me make supper anymore" Leonie, 17 (child of parent with traumatic brain injury, Sedgwick & Watt, 2000). Cognitive-communicative difficulties were noted to induce feelings of frustration on the part of the adolescent - "well sometimes it just irritates me – she tells me something and then I can't, I don't know what she's saying. And then it frustrates me and she says it over and over and over. And then I... it just frustrates me" (Wayne, 13: child of mother with traumatic brain injury, Sedgwick & Watt, 2000). It was suggested that the adolescents interviewed appeared to initiate fewer interactions with the injured parents due to frustration felt during communication breakdowns. In addition, it may be suggested that few quality interactions in families may further negatively affect relationships (Sedgwick & Watt, 2000).

Many studies have investigated the experiences of spouses, parents and children of individuals with cognitive-communicative disorders. Less attention, however, has been paid to siblings of individuals presenting with neurogenic communication disorders (Boschen et al., 2007; Degeneffe & Olney, 2008). Studies have shown that siblings may be significantly affected by a chronic physical disorder such as a brain injury (Gan & Schuller, 2002; Taylor et al., 2001). Intervention involving siblings is often overlooked (Degeneffe, 2009 & Boschen et al., 2007). It may be suggested that siblings may be placed in caregiving positions especially if a parent presents with depression

(Burton, 1975 as cited by Taylor et al., 2001). In addition, “parents may also use siblings as confidantes and sources of social support, thus adding potentially adverse developmental family and social burdens to the practical burdens of care” (Taylor et al., 2001, p. 961). Studies such as that conducted by Taylor et al., suggest that parents need to be aware of the siblings’ experience and attitudes towards the injury and the resultant communication difficulties affecting the family. This would allow for better adjustment in the family system (Taylor et al., 2001).

It may further be suggested that siblings may experience anxiety regarding the caring of the injured sibling should the parental caregivers no longer be able to fulfil this role (Degeneffe & Olney, 2008). Early intervention and counselling may allow for a smoother transition from sibling to sibling-caregiver and may minimise the stress experienced due to the responsibilities of a new role.

Communication with members of the extended family may also be negatively affected due to the neurological event or disease (Le Dorze & Signori, 2010). Threats (2010) states that the spouses of people with neurological communication disorders such as aphasia may be reluctant to discuss the difficulties experienced in the home and may be more willing to facilitate discussions surrounding the difficulties experienced by the person with the disability. In addition, it may be suggested that, for some family members, discussions about the difficulties experienced do very little to alleviate stress and ease the burden of caregiving. Families in these situations may require more practical assistance from extended family such as respite care (Le Dorze & Signori, 2010; Threats, 2010).

2.5. The importance of support from medical professionals, family and friends.

Another concern surrounding support received from extended family members, as stated by Threats (2010) is that the support offered may not be sincere, consistent and may not last past the crisis phase. This sentiment is echoed by an adolescent child of a mother who sustained a traumatic brain injury: “but it’s also frustrating because when the accident happened all the people said, when we need something just phone them and everything and then when we really need something, like just to get my mother from here to there just with a car, and then you phone them and they say no, sorry they can’t do it” (Wayne, 13 years old, Sedgwick and Watt, 2000).

Cultures differ in the way in which they manage stress and communication difficulties within the family. Accepting, offering or giving assistance without direct requests may be seen as a contentious issue in some cultures. Threats (2010) draws attention to the fact that seeking psychological counselling during times of stress may be frowned upon and seen as unnecessary or even extravagant. In addition, “the act of asking for help, even from family and friends, is highly influenced by culture” (Threats, 2010, p. 455).

The need for information-giving must not be ignored (Degeneffe and Olney, 2008; Le Dorze and Signori, 2010; Natterlund, 2010; Wallengren et al., 2008). Laroi (2003) explains that families need to be educated and reminded that many of the problems experienced by the individual and that family are physiological. This may be suggested to minimise the risk of personalising the behaviour and perhaps even preventing the person with the brain injury from becoming the scapegoat (Gan et al., 2006). Laroi

(2003) cautions, however, that therapists working with families must be aware of the different reactions – “those reactions that can be expected as a result of the brain injury, those that cannot be directly attributed to the brain injury but can be seen as normal reactions to the event, and finally reactions which are not related to the injury at all” (p. 177).

In addition, attention must be given to the communication environment in which the communication disorder exists – “if the communication environment is filled with tension or distress, then optimum communication may not be achieved and there could be a decrease in the level of communication effectiveness and satisfaction over time” (Threats, 2010, p. 456). This deterioration in communication may not be as a result of the cognitive-communicative difficulties but may occur as a result of tension or distress within the environment. This sentiment was echoed in studies conducted by Threats (2007) and Baylor et al., (2011).

2.6. Realistic goal setting and intervention plans

Realistic rehabilitation therapy goals, specifically speech therapy goals, including realistic expectations of speech improvement and the timing of discharge from speech therapy appears to influence communication within the home environment. Le Dorze and Signori (2010) found that spouses of aphasic individuals interviewed in their study continued to report being hopeful of further speech improvements many years post-stroke. In a study conducted by Threats (2010) it was found that the frequency and quality of conversations between aphasic and non-aphasic spouses decreased once

therapy stopped. It was suggested in this study, that this may have been affected by the individuals' perception of the likelihood of further recovery and these individuals may have assumed that therapy was terminated as further recovery was unlikely. For this reason, it may be suggested that termination of therapy and the reasons therefore need to be discussed with both spouses and the individuals receiving therapy. This further necessitates a collaborative relationship between the injured individual, the spouse and the speech and language therapist (Sorin-Peters, 2003). It may be suggested that a weaning-off period involving counselling and the explanations of home programmes should be instituted before therapy is terminated in order to allow for the carryover of skills and strategies targeted in therapy.

It is interesting to note that communication difficulties particularly surrounding therapy goal setting and information dissemination may also exist between the family members and medical staff (Azoulay et al., 2000; Bandeira, et al., 2011). In a multilingual-multicultural country such as South Africa, it may be suggested that many of these difficulties may arise or be compounded by language and cultural differences between these two parties. In addition, expectations surrounding the interactions may differ significantly and therefore, these expectations need to be discussed and evaluated during interactions.

In addition, to realistic goal setting, the appropriate assessment and intervention plans for families affected by neurological events such as strokes and TBIs need to be considered. Lutz and Young (2010) caution that “until we develop comprehensive caregiver assessment tools, case management interventions that support the needs and

preferences of the caregiver as well as the patient, and systems that provide continuity of care across the stroke trajectory, we will continue to put both patients and caregivers at higher risk for injury, depression, decreased health and well-being, and even death” (p. 158). Laroi (2003) explains that such an intervention approach requires better working relationships and understanding within the multidisciplinary rehabilitation team, particularly between the neuropsychologist, speech and language therapist and the family therapist. Rehabilitation team members need to gain better understanding of the different roles each plays in brain injury rehabilitation – not only for the injured individual but for the family and even the community at large (Fox et al., 2004). Furthermore, research is necessary in order to develop protocols to enable more effective interdisciplinary therapy approaches to improve functional outcomes for individuals with cognitive-communicative impairments and their families (Wallace, 2010).

Many studies have investigated the reactions of families to neurological incidents or disease associated with cognitive-communicative disorders but very few studies have resulted in the development of appropriate theoretical and clinical approaches to assessment and, more importantly, intervention in order to improve the family’s reactions to the sequelae of the brain injury (Boschen et al., 2007; Gan and Schuller, 2002; Joubert et al., 2010; Laroi, 2003; Le Dorze and Signori, 2010; Shanmugham, et al., 2009).

In my opinion, it is not sufficient for researchers to identify such problems. Research involving the development of culturally-appropriate therapy approaches to manage the

effects of acquired cognitive-communicative difficulties within a family setting is vital. Le Dorze and Signori (2010) state that because speech and language therapists possess expert knowledge regarding communication and the effects of neurogenic communication disorders on individuals and families, “these professionals should exert leadership in designing and implementing services that will ultimately promote the social participation of all people affected by aphasia” (Le Dorze & Signori, 2010, p. 1085).

2.7. The caregivers’ experience of loss

Guerriere and McKeever (1997) propose the idea that parents of children who have suffered neurological incidents may experience feelings of loss as they attempt to work through the realisation that the child before the incident was very different to the child after the neurological event. Other authors such as Kean (2010) have described the loss that family members experience as ambiguous. This relates to the idea that the loss refers to the physical presence of the child but the psychological absence of the child who once was.

The loss experienced by the parent caregiver may often not be given the status of grief afforded more clear-cut losses, such as the death of a child. This is largely because, to the broader community and sometimes even family members and friends, the injured child retains a physical presence in the family. Parent caregivers may therefore be disenfranchised from their grief. This may create a situation in which the parent caregiver cannot adequately mourn the loss of the adult child despite the significant

physical, communicative and cognitive deficits that exist after the neurological event. This may be likened to the experiences of family members of prisoners on death row, dealing with the attendant denial of the right to grieve a loved one who still lives (Jones & Beck, 2006).

Similarly, family members of adults with communication difficulties, particularly those of a degenerative nature, may experience feelings of loss and grief. Savundranayagam et al. (2005) conducted a study on the effects of communication problems on caregiver burden specifically related to dementia. They state that these family members often “face the challenge of maintaining relationships with persons who are physically present but not able to engage in appropriate social or verbal exchanges” (Savundranayagam et al., 2005, p. S54).

In addition, to the loss of the healthy child, studies have shown that caregivers can experience a loss of their own plans and dreams for the future (Buschenfeld, et al., 2009; Green and King, 2009). The studies conducted by both Buschenfeld et al. (2009) and Green and King (2009) investigated the experiences of partner-caregivers and their reaction to the permanent changes to their life plans. Studies such as the one conducted by Backstrom and Sundin (2007) suggest that parent-caregivers experience similar feelings regarding a changing future.

What becomes clear when considering the dynamics and characteristics of loss in such studies, is that there is something of a temporal warp related to the loss. Although the

neurological event may strike suddenly, it is finite and time-specific. To the parent caregivers the subsequent feelings of loss and grief resulting from the changes in their once healthy adult child are timeless and indefinite.

The acknowledged burden of care for these parent caregivers may be compounded by these feelings of loss and grief that may exist far beyond the acute stages of recovery.

2.8. Caregiving as a long-term responsibility

Authors have recognised that caregivers in the acute phase following a neurological event may be primarily concerned with their family members' survival (Falk-Kessler, 2011). It is suggested that caregiver fatigue and social isolation may arise in the later stages of recovery particularly if caregivers perceive that both they and their injured family members have been abandoned by healthcare providers, family and friends. In addition, the need for supervision and caregiving may frequently change in the first two years after the neurological event (Benge, et al., 2010) and although caregiving patterns may change over time, the need for fulltime caregiving following a neurological event such as a brain injury may extend beyond five years after the injury (Griffin, et al., 2012). Greenwood et al. (2009) suggest that there is a need to investigate caregiver experiences over time.

As already discussed, it is commonly accepted in many communities in South Africa that grandmothers will assume the parental responsibilities of children should the mother be unable to care for the child. This is very often due to HIV-related illnesses

and deaths. Connor and Bryer (2005) explain that “in a population affected by HIV, where many families have lost their parents, that role is then taken on by grandparents. This group is at most risk for stroke and vascular disease” (p. 200). Furthermore, studies have suggested that the prevalence of HIV infection among adults older than 50 years has increased significantly (Dobbs & Berger, 2009). This implies that these children may not only be affected by their parents’ death or illness, but may be further affected by the surrogate parents’ illness or even death. Financial resources may be then further stretched to cover rehabilitation needs.

In addition, many studies have focused on the immediate needs of caregivers (King & Semik, 2006). Few studies have investigated how the needs and experiences of family caregivers change over time (Thomas & Greenop, 2008). In addition, many studies have explored the experiences of young children with acquired cognitive-communicative difficulties (Bornman & Alant, 2002). Furthermore, attention has been given to the experiences of parent caregivers living with a child with a psychiatric condition (Aschbrenner et al., 2010). Maggs and Laguharne (1996) explain that there is a need to investigate the relationship between informal caregivers and their neurologically impaired family members as they age.

2.9. Measuring caregivers’ experiences

Caregiver strain and the caregivers’ perception of their quality of life may be measured using quantitative means, such as quality of life scales as well as qualitative means, for example thematic analysis.

After careful consideration of a variety of quality of life scales available, such as the WHOQOL measure (WHO, 1997), a qualitative research design was considered to generate more meaningful data regarding caregivers' experiences of caring in the South African context, in favour of quality of life scales, as when using restrictive rating scales, "we infer quality of life from a variety of indicators, many of which tell us something about life but nothing about quality" (Leplege & Hunt, 1997, p. 47). A criticism of quality of life scales is that, due to the restricted nature of these scales, the use of closed-ended questions does not allow for the participant to add viewpoints or additional relevant information pertaining to their perceptions of their quality of life. In addition, there may be a risk of the misapplication of scores which may impinge on the reliability of the research. The clinical significance of numerical scoring may not always be clear.

Few quality of life scales as well as caregiver burden indices regard the potential impact of communication difficulties on the injured person's family and or caregivers. Quality of life scales have been shown to comprise numerous items regarding physical limitations but neglect the potential impact of communication difficulties on the quality of life of the injured person's family members (Jones et al., 2008; Mahoney & Barthel, 1965).

2.10. Conclusion

From the extensive literature review conducted before commencing this study, there appear to be no known studies conducted in South Africa that have investigated the experiences of parent caregivers resuming the role of primary caregiver to their neurologically impaired adult child. Whereas many studies have examined the long-term toll of coping with a family member's traumatic brain injury or stroke, studies have not specifically examined the subjective burden and practical difficulties associated with parenting a neurologically impaired adult child. This study aims to fill that gap.

CHAPTER THREE

3. Methodology

3.1. Aims of this study

The main aim of this study was to explore and describe caregiver experiences of caring for an adult child with neurogenic communication difficulties within the South African context.

In addition, this study investigated:

- barriers and facilitators, stressors and resources specifically related to caring for an adult child in South Africa
- the caregivers' perception of their quality of life following their adult child's stroke/brain injury/brain tumour
- the life changes and choices made by older caregivers following their adult child's stroke/brain injury/brain tumour.

3.2. Research design

This study adopted a qualitative research design consisting of a semi-structured interview and a questionnaire developed by the researcher.

Both a semi-structured interview and a questionnaire including a functional status scale were used in order to gain information about the caregivers' experiences of caring for their adult child following a neurological event. The interviews focused primarily on the experiences of caring and probed areas related to barriers and facilitators in the parent caregivers' experiences. The questionnaire and functional status scale were used to gain an understanding the type of neurological event, details relating to the event, such as the age of the adult child, pre-injury occupational status as well as the functional physical and communication sequelae resulting from the neurological event.

The researcher selected the interviews as a method of obtaining subjective data regarding the parent caregivers' experiences of caring for their neurologically impaired child. The questionnaire and functional status scale were used as a means of obtaining more objective information regarding the adult child's neurological event and resultant difficulties.

Qualitative research designs are useful for examining certain aspects of human behaviour as they allow the voice of the participants to be heard and analysed. Qualitative research designs such as thematic analysis have been used to establish the perspectives of individuals living with different health issues, for example anorexia nervosa (Tierney & Fox, 2010), depression (Alderson et al., 2012) and HIV/AIDS (Siegel & Schrimshaw, 2002). In addition, thematic analysis has been used to identify and describe the experiences of families coping with specific family crises such as deployment in combat zones (Crow & Myers-Bowman, 2011) as well as the experiences of parents of children with special needs (Marshall & Goldbart, 2008;

Carter et al, 2002). It is suggested that this method has been used in such studies due to the amount and depth of information that can be gleaned from analysing affected individual's interview transcripts.

In contrast to more restrictive measures, qualitative research design methods involve the observation and questioning of participants and the analysis of their discourse. This approach may be said to have many advantages (Kelly, 2006). Firstly, interviews do not require the research participants to be literate. In addition, interviews do not restrict the length of answers literally due to space and time constraints. Interviews also allow both the researcher and participant flexibility in answering questions. The natural expression during the conversation between the researcher and the participant may be captured and analysed in the data analysis. The researcher is also able to probe areas introduced in interviews that are relevant to the focus of the study. Furthermore, although data analysis may be a lengthy procedure, interviews have a quick response rate.

Given the possibility for rich and varied experiences of parent caregivers of children who have been affected by neurological events, a qualitative research design involving the analysis of interview scripts was decided upon as the most effective means of tapping into and capturing these stories.

As the aim of this study was to describe personal experiences of caregiving, the importance of the participants' words and actions may be suggested to be vital in

developing an understanding of the parent caregivers' experiences of caring for their adult child (Maykut & Morehouse, 1994). Milne and Oberle (2005) explain that "qualitative research seeks not to reveal 'truth' but to generate insights. Qualitative researchers aim to describe and understand the nature of reality through participants' eyes with careful and ongoing attention to context" (p. 413). When considering the experiences of family caregivers, it may be suggested that context may play an important role in the caregivers' experiences of caring for a person who has suffered a neurological event. This idea is echoed by Diener and Suh (1997) who state, "objective quality of life focuses on using societal measure to objectively quantify and reflect people's objective circumstances within a given cultural context" (as cited by Yoong and Koritsas, 2012, p.609).

Although qualitative research designs are often used in the field of Humanities, such methodologies are not as clearly defined as some of the quantitative research designs (Milne & Oberle, 2005). In the field of Speech and Language Pathology research, it may be suggested that qualitative research design methods are poorly defined.

Due to the rigorous and systematic nature of the data collection and analysis processes, qualitative research has been criticised as being labour intensive and time consuming (Pope et al., 2000). It has been suggested that between six to twelve interviews may be necessary to achieve the desired amount of data necessary for this method of analysis (Guest et al., 2006). These authors caution, however, that "purposive samples still need to be carefully selected, and twelve interviews will likely not be enough if a selected group is relatively heterogeneous, the data quality is poor, and the domain of inquiry is

diffuse and / or vague” (Guest, et al., 2006, p. 79). With this in mind, twelve participants were interviewed for this study. Data collection was stopped once saturation had been achieved.

3.3. Participants

3.3.1. Access to participants

The researcher consulted with multidisciplinary therapy teams at various hospitals (state and private), acute care facilities and support groups. Parents of adult children who had sustained TBIs, brain tumours or strokes were identified. Participants will refer to either single biological parents or, where possible, parent pairs – of whom at least one participant in the pair would be a biological parent. In addition, due to the high incidence of step-parent families in South Africa (Statistics South Africa, 2005), step-parents who had assumed the role of caregiver to neurologically impaired adult step-children were also considered for this study.

The researcher via the research assistant / interviewer consulted with multidisciplinary therapy teams at various hospitals (state and private), therapy centres and support groups. Parents of adult children who had sustained TBIs, brain tumours or strokes were identified. Potential participants were also approached through neurorehabilitation therapists and group facilitators at various hospitals, therapy centres and support groups. These potential participants were then invited to participate in this study.

3.3.2. Participant inclusion criteria

For the purposes of homogeneity, specific inclusion criteria were used to identify possible participants for this study.

The following inclusion criteria were put forward for participation in the study in the original proposal:

- i. The participant must have been living with an adult child who had suffered a brain injury, stroke or brain tumour. The term adult child will refer to a biological or stepchild over the age of 18 years.
- ii. The adult child needed to have reached a level of financial independence by the time of the neurological event.
- iii. The adult child's neurological event must have occurred at least two years before the commencement of this research project.

Participants were then selected on the basis that they complied with all of the inclusion criteria.

3.3.3. Participant information

The table below provides information regarding the parent caregiver as well as the adult child.

Table 1. Participant Information.

<u>Code</u>	<u>Marital status</u>	<u>Couple / single parent</u>	<u>Age of parent caregiver</u>	<u>Age of adult child</u>	<u>Gender of adult child</u>	<u>N E</u>	<u>Age at Event</u>
AA	Divorced	Single parent	MF: 58 years	26 years	Male	TBI	20 years
BB	Divorced	Single parent	MF: 62 years	36 years	Female	BT	26 years
CC	Widowed	Single parent	MF: 66 years	44 years	Female	CVA	29 years
DD	Married	Parent pair	FF: 61 years MF: 53 years	30 years	Male	CVA	26 years
EE	Married	Parent pair	FF: 82 years MF: 82 years	59 years	Male	TBI	46 years
FF	Divorced	Single parent	MF: 68 years	39 years	Female	BA	37 years
GG	Married	Parent pair	FF: 74 years MF: 70 years	47 years	Female	CVA	36 years
HH	Married	Parent pair	FF: 70 years MF: 62 years	39 years	Male	TBI	30 years
II	Married	Parent pair	FF: 71 years MF: 66 years	43 years	Female	CVA	40 years
JJ	Married	Single parent	MF:: 48 years	25 years	Male	TBI	22 years
KK	Married	Parent pair	FF: 74 years MF: 67 years	38 years	Male	TBI	31 years
LL	Married	Single parent	MF: 60 years	23 years	Male	TBI	20 years

Key for Table 1:

FF – Father Figure

MF – Mother Figure

TBI – Traumatic Brain Injury

CVA – Cerebrovascular Accident

BA – Brain Abscess

BT – Brain Tumour

Overall, eighteen participants were interviewed in this study. This included six single parents and six parent pairs. The participants were natural parents of the neurologically impaired adult child and ranged in age from 48 years to 82 years. The age of the adult child ranged from 20 years to 46 years.

Of the twelve adult children, six had sustained TBIs in motor vehicle accidents and four had suffered cerebrovascular accidents (CVA). One adult child had been diagnosed with a cerebral tumour and one adult child suffered brain damage from a brain abscess. All the pathologies identified resulted in reported physical, cognitive and communicative difficulties which decreased the adult child's independence and prohibited the adult children from staying alone. In addition, all the participants reported marked difficulties related to activities of daily living and financial management.

3.4. Research assistant

As several participants were known to the researcher, the interviewer (not the researcher) approached possible participants and invited them to participate in this study. This was done to minimise any coercion or forced participation.

A registered lay counsellor was selected as a research assistant / interviewer as due to the personal nature of the questions posed to the participants and the possibility of generating emotional responses. In addition, the researcher assistant approximated the parent caregivers' age and stage of life. This was considered important as it was felt

that the participants would be more comfortable discussing parenting issues and emotional experiences with a peer.

The interviewer agreed to participate in this research project and was compensated for her time and travelling expenses at a rate agreed upon by the researcher and the interviewer. In addition, the need to maintain confidentiality of the participants and any information obtained during the research process was explained to the interviewer.

The research assistant's role was to approach possible participants for the study, either telephonically or in person. In addition, the research assistant was required to carry out the individual interviews with the participants using the interview guidelines as a basis for discussion. In addition, the research assistant was responsible for ensuring that the relevant consent forms were signed and that the interviews were audio-recorded.

3.5. The pilot study

A pilot study was conducted before commencing the larger study. The pilot study was undertaken in order to:

1. Assess the feasibility of the research project in terms of time taken to complete the questionnaire and interview and resources (financial, personnel) necessary.
2. Identify logistical problems which may occur using the proposed data collection, transcription and analysis methods.

3. Assess the usability and effectiveness of the interview guidelines and questionnaire in obtaining the relevant data and to identify ambiguities and difficult questions in the interview guidelines and questionnaire.
4. Appropriately train the research assistant / interviewer.
5. Assess the proposed data recording (audio), transcription and analysis techniques to identify potential problems.
6. Collect preliminary data for analysis.

These aims are in line with those recommended by Thabane et al. (2010) and Peat et al. (2002).

The researcher made use of the protocol for data collection, transcription and analysis detailed in the research proposal. This included the administration of a questionnaire developed by the researcher (Appendix One). In addition, the independent interviewer conducted a semi-structured interview with a parent caregiver of an adult child who had suffered a brain tumour and presented with resultant physical, cognitive and communication difficulties. The interviewer made use of the interview guidelines in Appendix Seven. The interview was audio-recorded for transcription and analysis by the researcher.

The pilot study suggested that this research project was feasible in terms of time for data collection, transcription and analysis as well as the resources required. In addition, the data collection, transcription and analysis methods used were deemed appropriate and yielded relevant data for transcription. No ambiguities or difficult questions were

identified in the interview guidelines and questionnaire. No changes to the interview guidelines or questionnaire were deemed necessary. In addition, the identified independent interviewer was considered appropriate for this study.

Following the analysis of the data obtained in the pilot study, it was decided that the study piloted well. The research design was then implemented in the data collection and analysis of the participants identified in this study.

3.6. Ethical considerations

3.6.1. Ethical consent

Prior to commencing the data collection, ethical consent was obtained from the University of the Witwatersrand Human Research Ethics Committee (Clearance Certificate Protocol number H120806, Appendix Two).

3.6.2. Consent from the research assistant / interviewer

Signed consent to act as a research assistant / interviewer was obtained from the research assistant (Appendix Three). This included information regarding the aims and nature of the study and the role of both the research assistant and the participants in this study. In addition, travelling expenses and reimbursement for services rendered were discussed. The research assistant was assured that her participation was entirely

voluntary. In addition, a separate section on confidentiality was included in the information form.

As stated earlier in this chapter, a research assistant / interviewer was used in this study to prevent any potential participant coercion as several participants were known to the researcher.

3.6.3. Consent from the participants

Once possible participants had been identified, these possible participants were approached by the research assistant. The aims and rationale of this study were explained to the possible participants. The participants were given a letter describing the research project (Appendix Four).

Separate information sheets (Appendix Four) and participant consent forms were given to the participants in this study (Appendix Five). This included permission for the interviews to be audio-recorded. It was explained that participation in this study was entirely voluntary. The participants were informed of their right to withdraw from the study at any time as well as their right to refuse to answer any questions. In addition, confidentiality was discussed. The participants were then required to sign the letter of consent (Appendix Five).

3.6.4. Confidentiality and anonymity

The following steps were taken to preserve the confidentiality and anonymity of the participants in this study:

- Identifying information pertaining to the geographical location of the participants was removed from the demographic information forms. In addition, all other identifying information was removed.
- Data in the results and discussion section was not linked to the participant codes.
- Transcripts are presented in random order, unlinked to the order in which the participants were interviewed.

3.6.5. Referral protocol

It was acknowledged that the nature of the interview questions and the discussion surrounding caregiving may give rise to emotional responses on the part of the parent caregivers. For this reason, a list of appropriate support services including support groups, counsellors and psychologists, was made available to the research assistant so that issues which potentially could surface during the process of data collection could be dealt with efficiently and effectively. The use of any of these services would be at no cost to the participants.

Although most interviews did elicit emotional responses and discussions, none warranted immediate referral to counselling services or support groups.

3.7. Data collection

3.7.1. Case history questionnaire

A detailed case history of the adult child's neurological event, subsequent medical and therapy management as well as family roles was taken prior to interviewing the parent caregiver participants. In addition, premorbid activities and employments were noted. The participants were asked to complete a written questionnaire (Appendix One). This questionnaire broadly explored details relating to the adult child's neurological event and subsequent inclusion into the parental home. This questionnaire was used to gain an understanding of the adult child's functioning and participation in work and social environments prior to the neurological event. The areas probed in the questions in the questionnaire were similar to the questions presented in the Stroke Self-efficacy Questionnaire (Jones et al, 2008) and the Barthel Index (Mahoney & Barthel, 1965).

3.7.2. Functional status scale

I devised a scale that comprised twenty items based on the functional difficulties that may commonly be associated with acquired neurological conditions (Appendix Six). As with the questionnaire, these items were similar to those found in the Stroke Self-efficacy Questionnaire (Jones et al., 2008) and the Barthel Index (Mahoney & Barthel, 1965). These included physical and cognitive abilities related to activities of daily living and financial management skills. Unlike the Stroke Self-efficacy Questionnaire (Jones et al., 2008) and the Barthel Index (Mahoney & Barthel, 1965), the scale used in this study included items relating to functional communication abilities, including the ability to use and understand spoken and written language.

It is suggested that these functional difficulties including those related to physical, cognitive and communication impairments may have a negative impact on caregivers' quality of life. In addition, an inability to carry out functional tasks and activities of daily living may add to caregiver strain (Hilton, 2012).

3.7.3. Semi-structured interview

Perceptions of parent caregivers' experiences of caring for their neurologically impaired adult child were obtained within the framework of a semi-structured interview. The interview guidelines probed the caregivers' experiences of caring for their adult child following a neurological event (Appendix Seven). Questions posed investigated whether or not any cognitive-communication difficulties impacted on communication within the home. In addition, caregivers' expectations regarding life changes and plans were probed by the interviewer. The questions were structured in a way as to elicit information regarding any resources or services that had positively impacted on their caregiving experiences.

The interview guidelines comprised five key open-ended questions. These were grouped thematically into themes exploring the caregivers' experiences relating to changes in the family since the neurological event, any possible communication difficulties, the caregivers' expectations of their own lives before the adult child's neurological event, resources that have enhanced their caregiving experiences and information they would have found useful in the acute stages of the adult child's rehabilitation.

Due to the impact of context on both communication and relationships, a semi-structured interview was used to gain insights into the experiences of parents following their adult child's neurological event (Kelly, 2006). This allowed the participants time and opportunities to express their unique perceptions of their quality of life and the factors that may have impacted on their caregiving experiences. Most importantly this method of data analysis does not merely examine the participants' responses in isolation but allows for the inclusion of the influence of the social context in the interpretation of the analysis (Attride-Stirling, 2001).

Participants who met the specific inclusion criteria and consented to their participation in the research project were interviewed by a trained research assistant. Interviews were selected as the method of data collection as they do not require the participants to be literate. In addition, interviews do not restrict the length of the answers in terms of space and time. Interviews also allow both the researcher and participants flexibility in answering questions (Newton, 2010).

3.7.4. Data collection procedure

Semi-structured interviews were conducted with each participant by the research assistant. Each interview lasted approximately 60 minutes. This included time to complete the questionnaire and interview questions. Information was obtained in a one-to-one interview set-up. This was done to minimise the effect of other individuals on the participants. Interviews took place in the participants' homes.

Responses were recorded by means of a digital voice recorder to ensure accurate transcriptions. Expressed consent (written) from the participants was obtained allowing the researcher to audio-record the interviews (Appendix Five). As the research assistant / interviewer and all of the participants were fluent in English, the interviews were conducted in English. The interviews were transcribed by the researcher according to the guidelines suggested by Braun and Clarke (2006).

3.8. Rigor

According to Krefting (1991) the rigor of a qualitative study refers to the trustworthiness of the research. Krefting (1991) states that it is vital to consider the four aspects of trustworthiness as described by Guba (1981). These include aspects related to (a) truth value, (b) applicability, (c) consistency and (d) neutrality. With these aspects of trustworthiness in mind, the researcher considered and employed various methodological strategies in order to enhance the rigor of this study.

In order to accurately present the parent caregivers' experiences of caring for their neurologically impaired adult child, a triangulation of methods was employed by the researcher. This method is suggested by authors such as McNeill and Chapman (2005) and Krefting (1991) in order to increase the reliability of a research tool and the validity of the data collected. In this study, the researcher made use of the following three methods in order to obtain information regarding the research question:

- i. Semi-structured, open-ended interviews were held with each participant. As described earlier, these interviews explored the parent caregivers' experiences of caring for their neurologically impaired adult child.
- ii. Analysis of the case history questionnaire which gave the researcher information regarding the details of the neurological event and information specific to the adult child.
- iii. Analysis of the functional status scale which identified difficulties related to the adult child's functional abilities including their ability to participate in activities of daily living, financial planning and communication tasks.

The interviews were conducted in naturalistic settings, in the parent caregivers' homes. Each interview focused on the individual participant's experience of caring for their adult child. Although similar experiences were noted in the transcripts, each interview was seen as a description of an individual experience. In terms of applicability, however, sufficient data was obtained in order to allow the comparison of these experiences between participants. This is in line with the guidelines suggested by Lincoln and Guba (1985).

In order to maximise transferability and generalizability of the results obtained in this study, the researcher kept a detailed record of the decisions made and steps taken during the research process (Paulus et al., 2008).

The interviews were conducted by a third party in order to minimise the risk of researcher bias as well as to ensure neutrality. To further prevent any researcher bias, the interviewer was unknown to participants and was a registered lay counsellor.

According to the framework and strategies proposed by Whittemore et al. (2001), the researcher underwent an ongoing process of reflection in order to enhance the rigour of the study. This included awareness of “(1) authenticity, or attention to the voices of the participants, (2) credibility, a reflection of how believable results are, (3) criticality, the critical appraisal of every decision made throughout the research process and (4) integrity, demonstrated by on-going self-reflection and self-criticality of the researcher” (Milne & Oberle, 2005, p. 414).

Newton (2010) cautions that the validity of the results obtained in a qualitative research study may be threatened if the interviewer includes leading questions in the interview. During the research assistant’s training, this was explained and discussed with the research assistant. In addition, as the researcher did not conduct the interviews, the risk of the researcher’s preconceived ideas influencing the participants’ responses was not an issue in this study.

3.9. Data analysis

Analysis of the data obtained from the interviews involved the repeated listening of the recorded interviews and rereading of the transcripts in order to identify possible themes related to the caregivers’ experiences. This involved the following processes described

by Green et al. (2007): “immersion in the data, coding, creating categories and the identification of themes” (p. 546). The context of the interviews as well as the relevant information gleaned from the participant questionnaire and functional status scale were incorporated in the analysis of the data set.

The written interview transcripts were then analysed by the researcher using the process of thematic analyses which “seek to unearth the themes salient in a text at different levels, and thematic networks aim to facilitate the structuring and depiction of these themes” (Attride-Stirling, 2001, p. 387). The researcher then conducted a thematic analysis on the data such as that described by Braun and Clarke (2006) and Attride-Stirling (2001).

According to Braun and Clarke (2006), a theme identified in interview transcripts is a patterned response that represents meaningful information within the data set. These patterned responses are related to the research question. The researcher identified such themes using the six phases of conducting thematic analysis as described by Braun and Clarke (2006). These six phases included:

- i. Becoming familiar with the data by careful rereading of the interview transcripts.
- ii. Generating initial codes to represent possible themes in the data set. The researcher used coloured marker pens to highlight pieces of text that related to possible themes.
- iii. Searching for possible themes in the data set.

- iv. Reviewing the themes identified in the data set. In addition, the researcher identified each individual theme but also considered how themes related to each other.
- v. Defining each theme and then providing each theme with a name within the data set.
- vi. Producing a report detailing the various themes contained within the data set.

Through thorough and repeated reading of the transcripts together with information gleaned from the case history questionnaire and functional status scales, the emerging themes were coded and grouped together into the following categories:

- The caregivers' experience of loss.
- The caregivers' fears.
- Sources of support.
- The need for the appropriate information at the appropriate time.

The themes were explored and analysed and sub-themes relating to the main themes were identified. The themes were viewed individually and in the context of South Africa. The emerging themes were then viewed in relation to each other and in relation to the experiences of caring for an adult child in the South African context.

CHAPTER FOUR

4. Results of this study

4.1. Introduction

This chapter will explore the interview transcripts obtained from the participants. The interview guidelines used in the semi-structured interviews yielded a large amount of recorded data. The thematic analysis of the data, as described in the previous chapter, identified four major themes relating to the parents' experiences of caring for their neurologically impaired adult child in the South African context.

Upon reflection of the results obtained from this study, it may be suggested that the research methods employed in this study, namely the participant questionnaire, the functional status scale and the semi-structured interviews proved to be successful in obtaining information regarding the parent caregivers' experiences of caring for their neurologically impaired child. The semi-structured interviews, in particular, yielded a significant amount of rich data for analysis. The analysis of the interview transcripts provided the researcher with valuable personal perspectives on caring for a previously independent adult child.

Another factor that may have contributed to the richness and amount of data obtained in this study is the effect of conducting research in the participants' natural setting. The participants were interviewed in their homes. Kelly (2006) explains that qualitative

researchers strive to interpret and make sense of phenomena and experiences as they occur in the real world. For this reason, it is beneficial to study the participants in their natural setting.

In addition, the research assistant / interviewer proved to be very valuable in eliciting responses from the participants during the semi-structured interviews. It was evident in the audio-recordings of the interviews that the research assistant / interviewer was able to establish a rapport with the participants during the interviews. The research assistant / interviewer was able to elicit responses to the questions in a natural exploratory conversation without making the participants feel overwhelmed. As the research assistant / interviewer was a mother of three adult children, a feeling of shared interest was noted upon listening to the audio-recorded interviews.

The four themes and specific subthemes are outlined in Table 2. In addition, each main theme and its corresponding subthemes are discussed in detail in the following sections. Quotes stated by the participants and related to both the main themes and the subthemes are highlighted.

Table 2. Emerging themes in the caregiver interviews.

Loss

“This is not my child”

- Physical differences
- Cognitive-communicative difficulties

“This is not how it’s supposed to be for me at my age”

Changes in the family

- Role changes
- The effect on other family members

Caregivers’ fear

- Fear of the future
- Fear of the unknown
- Fear regarding caring for the adult child

Sources of support

- Family and friends
- Abandonment

The need for appropriate information at the appropriate time.

4.2. Loss

All the caregivers interviewed in this study reported that they had experienced a sense of loss since their adult child's neurological event. This loss was related to the loss of the healthy, uninjured child, the loss of the caregivers' own plans for the future as well as the losses experienced as a family.

4.2.1. "This is not my child"

The first main theme centred on the parents' perception of loss - that the adult child after the neurological event was very different to the adult child before the neurological event. Two sub-themes were identified in this theme – those being the **physical differences** in the adult child and the **cognitive-communicative difficulties** displayed by the neurologically impaired adult children.

The sudden nature of the neurological event was described by Participant DD. The idea that the parent caregiver did not expect her child to have a stroke is highlighted in the quote below. It is interesting to note that she draws a comparison between young and healthy and further infers the popular opinion that strokes happen to older people.

When something like this happens to your child, hey, it's the biggest shock, you can't actually believe it... Children are supposed to be healthy and if anything happens it's supposed to be to you not them.

Participant DD

All the participants interviewed in this study reported that they noticed significant physical, cognitive, communication and personality differences in their child since their adult child's neurological event.

4.2.1.1. Physical differences

I first saw him in the ambulance when we heard about the accident and there was just blood everywhere and I wouldn't have recognised him had I not known it was my child.

Participant LL describing her initial shock at seeing her child at the scene of his accident.

Participant KK highlighted that the physical difficulties noted immediately after the accident persisted and continued to have an impact on her child's movements and participation in activities of daily living. In addition, she refers to the idea that her son "wasn't himself", referring to the difference she perceived between her son before the accident and her son after the accident.

His movement – he wasn't himself. His movements were slower and everything... climbing up and down stairs and things like that.

Participant KK

These difficulties were reported to persist after the initial hospitalisation and an inpatient rehabilitation programme. This highlights that few rehabilitation therapists deem it necessary to discuss the process involved in the initial stages of recovery following a neurological event – that being that the physical difficulties and subsequent

limitations imposed on the injured person's ability to participate in activities of daily living are often noted long after the rehabilitation programme has ended.

Furthermore, these physical changes gave rise to an awareness of safety concerns for parents. Participant KK went on to describe how, due to the nature of her son's physical difficulties and the risk of self-harm, he had to be supervised during all activities

Of course we were always very cautious when he went to have a shower. We didn't allow him to lock the door, or anything like that, we were also worried. We are always worried. Somebody has to be with him all the time.

Participant KK

The parent caregiver's experience of worry and concern is highlighted in the quote above. It is interesting to note that Participant KK changes from speaking in past tense, "we were also worried" to include the feelings of worry that she experiences presently when considering his physical abilities and risk of injury, "we are always worried".

This idea of concern for the adult child relates to the parent caregivers' experiences of receiving a helpless and dependent child back into the home, rather than the adult child they knew before the neurological event. This change from independent adult to dependent child is experienced as a sudden and unexpected change.

All of a sudden, we got a baby back home and then we had to start again and start getting him back to being independent.

Participant JJ

Participant JJ stated that, due to the severity of her son's physical and cognitive difficulties following his accident, she felt as if she was starting to raise her child from a baby all over again. A loss of independence on the part of the injured adult child and an increased dependence on the parent caregiver/s of the injured adult child was identified in many of the interviews. As stated in earlier chapters, studies have shown that individuals who present with executive functioning difficulties related to planning, initiation, problem-solving, self-monitoring and error correction, may have significant difficulties in regaining independence following a neurological event. This is suggestive of the difficulties related to learning and using alternative movement strategies to compensate for physical deficits such as limb weakness and balance problems experienced by the survivors of neurological events (Chung et al, 2013).

And then my husband would take him through to work and go fetch him again – he wasn't allowed to drive until he went for the test again.

Participant KK

As discussed in earlier chapters, TBIs are also more likely to result in executive functioning difficulties which require more supervision from caregivers. Participant KK described the increase in responsibilities for her husband due to their son's physical difficulties. It is suggested that the physical needs and need for supervision of these adult children not only place demands on the parents' time but also add to the responsibility of caregiving. Interestingly, none of the parents interviewed reported any financial costs or inconveniences involving adapting the home environment to the physical needs of the adult child.

4.2.1.2. Cognitive-communicative difficulties in the adult child

The participants in this study described communication, cognitive and behavioural changes in their adult child since the neurological event. Particularly concerning to the parents were the behavioural and personality changes that were evident in their injured child. These behavioural issues included episodes of swearing, shouting, poor behavioural monitoring and a child-like response to confrontation. The participants in this study reported that these behavioural disturbances resulted in their experiencing sadness and frustration, once again emphasising the difference between the child before the incident and the child after.

That child that's standing there who's going mad is not my son. He's not a part of me. The one that comes and hugs me and makes me coffee, that's my child. But this one is not. The one screaming and shouting and swearing. This is not my child.

Participant HH

Miller (1993) describes the negative and challenging behaviours that adults who have suffered TBIs frequently display after a brain injury. Similarly Participant HH acknowledged that she had difficulty in recognising her son during his temper outbursts and felt that he was a stranger to her in those moments. Her experience highlights the childlike temper tantrums that can occur in a brain injured person. Miller (1993) describes this behaviour as that of a complaining and demanding child. But there is a significant difference. The badly behaved brain-injured individual is not a child and due to the cognitive difficulties resulting from his traumatic brain injury, he does not possess the cognitive or social skills to modify this behaviour or prevent it from manifesting in such interactions. This idea is echoed by Miller (1993 p. 112) who states

“but even children eventually learn which behaviours lead to aversive consequences and should therefore be avoided. Because of deficits in learning and memory, however, brain-injured patients typically fail to learn from their mistakes. They don’t remember the consequences of their actions (or indeed their actions themselves); therefore, they tend to get into the same kinds of trouble again and again”.

Other behavioural difficulties, such as those resulting from executive functioning deficits, are frequently identified in individuals who have suffered brain injuries (Constantinidou et al, 2012). Such deficits were highlighted by Participant HH when describing her son’s inability to monitor and modify his behaviour following his traumatic brain injury.

We have an alarm, and if that alarm goes off it says, it’s enough. Then you know. (son) does not have that when it comes to his violent outbursts. He doesn’t have it when it comes to his eating habits. There is nothing that says to him “Whoa, enough is enough”... sometimes it is funny and you can actually smile about but sometimes it is heart-breaking. He cannot reason with you especially if he is very angry.

Participant HH

Furthermore these deficits relating to disinhibition and the inability to monitor one’s own may persist long after the acute stages of recovery (Chung et al, 2012; Lippert-Gruner et al, 2006). As discussed in Chapter Two, Ergh et al.(2002) state that personality changes such as those described by the participants in this study are common and manifest in different ways such as emotional, cognitive and behavioural difficulties. Executive functioning difficulties such as those reported by the parent-

caregivers interviewed in this study, have been shown to have a negative effect on the rehabilitation process (Constantinidou et al, 2012).

Participant LL reported that she had noticed the effects that her son's behavioural difficulties and personality change had on others around him, particularly his girlfriend.

I would say he gets a little bad tempered at times, because they told us at the time that the area of the brain that was damaged may cause certain things like that. So he is very short-off sometimes. I feel sorry for his little girlfriend sometimes, because he gets rather moody. But we just put him in his place and then he realises.

Participant LL

Participant LL stated that she was aware that her son may display personality changes. She further reported that she was concerned that his girlfriend bore the brunt of her son's emotional outbursts and, perhaps, did not have the same understanding as she did regarding her son's behavioural difficulties. This comment highlights the importance of considering the individualistic impact that cognitive-communication difficulties have on both the person with the neurogenic communication disorder, the family as well as significant other people in the injured person's life.

Participant AA described her son's cognitive-communicative difficulties involving delayed processing of information and how this negatively impacts on her ability to have meaningful conversations with him. In the quote below she comments on the lack of spontaneity in their interactions and interestingly uses the words "awkward" and "odd" to describe their conversations. This is in contrast to what one would expect

conversation to be between two adults, where a more meaningful exchange of information would occur.

He'll talk to me as if it's (something that happened a while ago) just happened but then it's taken him 2 or 3 months to process, to really mull this over and think about why it shouldn't work and why it shouldn't have happened and that sort of thing and so it does make it awkward, because you can't really sit and have a real conversation with him either – you have these odd little conversations.

Participant AA

Participant BB echoed the sentiments elicited by Participant AA and went on to describe how the need for consistent reminders due to short-term memory difficulties resulted in her experiencing frustration during interactions with her daughter. It is interesting to note that even though she describes the communication between her and her daughter as “pretty good” the cognitive sequelae, for example her daughter’s short term memory loss, is seen as negatively impacting on her interactions with her daughter and is frustrating for her.

Our communication is normally pretty good but well since the operation, ok, her short-term memory is virtually, well it's non-existent. Ja. She will not remember what she had for lunch today. It's not that she's not trying to. She does try to remember. But she just doesn't. So on that score, um, the repetition does get frustrating.

Participant BB

Participant EE reported a similar experience with her brain injured son. She explained that although his conversational abilities were adequate for daily interactions, she

experienced frustration when constantly having to repeat information due to her son's short-term memory difficulties.

He's pretty good at conversation but his short-term memory – you can tell him your name now and two minutes later he'll say "what's your name?"

Participant EE

4.2.2. "This is not how it's supposed to be for me at my age"

Because of the physical and cognitive-communicative difficulties resulting from the adult child's neurological event and the sudden re-dependence on the parents for basic needs and care needs, the parents interviewed described another type of loss – the loss of their own plans and dreams for the future. The words of Participant II in the quote below capture this experience of loss.

I actually said to my friend the other day I always said when I retire one day, my house will be spotless, absolutely spotless with no dog hair, no toys lying around... we were thinking of selling the house, going into a little townhouse in a secured area We can't do that anymore because we don't know what the future holds for us.

Participant II

As discussed in Chapter Two, family caregivers often experience a loss of their own plans and dreams for their future after they have taken the responsibility of caring for an injured or ill family member. All the participants in the study made mention of the fact that their lives following the child's neurological event were different to what they had expected them to be at their age. Again, all the participants drew clear distinctions

between what life was like for them before and after their child's neurological event. In addition, many participants compared their current living situations to what they had expected them to be at their age.

She (daughter) had to come and live with us and she wasn't living with us, and her daughter had to come and live with us. I used to stay alone.

Participant GG

In this study it was found that many of the adult children returned to their parents' home following the neurological event, such as Participant GG's daughter returning to her parents' home following a cerebral abscess. This resulted in significant changes for both the parents and the adult child in terms of financial obligations, caregiving for the adult child and, in some cases, the responsibility of caring for grandchildren.

I mean I didn't think that I would be having a 28 year old staying in my home still, you know, he would probably have been married at this stage.. you know.. and have a child or whatever which is probably not going to happen but he's going to be living with me for whatever time, probably for the rest of my life.

Participant AA

In the quote above, Participant AA describes the reality that her caregiving responsibilities to her son may not be short-term. Rather, she describes the feeling of being resigned to the fact that her son may be dependent on her for the rest of her life. This highlights the idea that there is no perceived end-point when considering caregiving for an adult child. The caregiving needs of the child and the parents' responsibility to the child may be accepted as being necessary for "as long as it takes".

In this quote, the mother of the young head-injured man describes that there are no other caregiving options for her son. She also touches on the idea that he may have had a very different life had it not been for the accident. He may have been married. This further highlights the idea of loss – the loss of seeing an adult child married and living independently.

Caregiving takes time. Relationships are maintained through time spent with others. Time dedicated to one member of the family means less or limited time for other members of the family.

My husband and I don't get so much time together... I thought it would be my husband and I retired and ... doing whatever we want to do and it isn't like that at all.

Participant GG

Here, Participant GG comments on the effect her adult child living with her had on her relationship with her husband. Once again there is a loss – a loss of time available for the parents of the adult child to spend time doing things together in their retirement. In this case, Participant GG suggests that she may be not be able to participate in activities that she wants to due to time and perhaps financial limitations resulting from her caregiving responsibilities.

I thought at last I had time for myself and I had started travelling with my friend of my own age such that last year when my group went overseas, I didn't go with them because I had (daughter) to look after.

Participant GG

The parents' future plans often need to be revised to include the neurologically impaired adult child.

We were planning now this is going to be us. We young enough to go out and now, all of a sudden, we got a baby back home and then we had to start again and start getting him back to being independent.

Participant JJ

A study conducted by Raver et al.(2011) recognised informal caregivers' attempts to balance family, work and satisfaction of personal life goals. It is suggested that the parents interviewed in this study continue to struggle to try to balance their own needs and goals with that of their injured children.

4.2.3. Changes in the family

Many of the participants interviewed in this study described the effects that their adult child's neurological event had on the family as a whole, and not just on them as the caregivers.

(daughter) was living with us with her three children with the thought that later on they'd go on their own but then she had the stroke and, as far as finances and everything is concerned, it has changed our lives because um... because of the cost of living we need to feed them and in some cases, clothe them and (daughter) cannot go back to her job because she cannot use her hand properly.

Participant II

Of interest was that changes in the structure of the family did not necessarily occur following the adult child's neurological event, as in the case of Participant II. As discussed in Chapter Two, intergenerational families are common in the current South African context (Schatz et al., 2011) and may occur not only as a result of illness or disability within the family. Participant II commented that an intergenerational family structure was present in the family before the neurological event but that due to the adult child's cerebrovascular accident, the older parent caregivers need to continue caring for their child and grandchildren. The quote above makes mention of the fact that Participant II thought that there would come a time when her daughter and grandchildren would move out of her house but that due to her daughter's stroke this was no longer possible.

Both participants FF and II reported that they had assumed the role of mother and caregiver to their grandchildren since their adult child's neurological event.

I am now the mother for a four year old very buoyant young girl.

Participant FF

As discussed in Chapter Two, the notion of grandmothers becoming primary caregivers for their grandchildren is common in South Africa and is increasing worldwide (Park, 2005). A study conducted in Botswana by Thupayagale-Tshweneagae (2008), for example, found that grandmothers who assume the role of primary caregiver to their grandchildren understand that this role change is necessary and often occurs in a crisis. The researcher in this study proposes that in such cases, grandmothers may need to undergo "re-parenting training" as there is a generation gap between the first and second

episodes of their roles as parents. This may alleviate some of the stress associated with parenting at an older age and may facilitate adjustment to the new family structure. This was noted in the experiences of both Participants FF and II.

It was interesting to note that Participant II reported that, despite the additional caregiving responsibility she has had to bear, she experienced her young grandchildren as a support and not a burden.

I don't know what's helped me the most – I think, maybe my grandchildren because they, I'm so busy with them and they are so busy with me that I must admit, a lot of it takes my mind off (daughter).

Participant II

Financial resources in such families frequently need to be stretched to cover rehabilitation needs, childcare needs as well as every-day running costs in the home. Participant FF described how the role of financial provider was transferred to her after her adult child's illness. Further analysis of the transcription of the interview with Participant FF also highlights a growing trend in developing countries – that of female-headed households.

I'm a pensioner so I had to live off jobs that I was doing about a year since she became ill. My financial advisor also gets worried because it becomes difficult for him to say "don't do this" because he understands that this is for my child.

Participant FF

According to statistics, nearly half of all households in South Africa are headed by women (Department of Health, Medical Research Council, Orc Macro, 2007). Of interest in this study is that four out of the twelve participants interviewed were women who were also sole providers for their families.

Role changes within the family are common and frequently necessary after a member of the family has suffered a neurological event. This is largely due to the effect that the physical, cognitive and communication difficulties have on the injured person's ability to adequately fulfil his or her role in the family (Kosciulek, 1995). Participant II reported that the cognitive communication difficulties resulting from her daughter's stroke necessitated her taking over her adult child's role as mother and caregiver to her own children. This idea of grandparents parenting their grandchildren is not without difficulties. A study conducted by Letiecq and colleagues (2009) found that there are few legal and policy protocols in place to empower and support grandparents to make the necessary decisions regarding their grandchildren's care when the parents are present but unable to do so.

Although role changes within all the families interviewed were reported, of interest is that Participant II explained that she encourages her adult child to reclaim some of her parenting roles and responsibilities, but due to the cognitive and communication difficulties resulting from the stroke, this is not possible.

She can't talk properly, um, but I think she's got a bit of a problem with me because all of a sudden, she has the stroke and I took over everything – I took over her children because I look after them. Um, she is here to help but I'm now the main figure – I'm like now the mother figure and she's just looking at what I'm doing with her children and I have explained to her and said to her "It's your children – you see that their bedrooms are tidy, you see that they do their homework, you see that they bath, shower, or whatever" but because of a bit of brain damage, um, she forgets. I don't know what to say because I don't know how her mind works now.

Participant II

Similarly, Participant HH also reported that she attempts to restore the roles and responsibilities within the household and in relationships. This quote refers particularly to the establishment of rules and boundaries within the mother-child relationships. It is suggested that due to the her child's executive function difficulties, Participant HH feels that she needs to constantly establish the boundaries and rules for appropriate behaviour in the mother-child relationship.

You need to remind him, I am not your friend. I am your mother and in that moment he doesn't really understand. He just walks out but sometimes he will come back and apologise and give me the best flower in the garden.

Participant HH

Interestingly, studies have been conducted to investigate mothers' and their adult daughters' perceptions of their relationships. A study conducted by Bojczyk et al. (2011) found that in uninjured mother-daughter-relationships themes relating to generational changes, conflict and maternal pressures were identified as having a

negative effect on the mother-daughter relationship. It can be suggested that when considering the effects that the cognitive-communicative difficulties have on the injured individual and the relationship as a whole, these issues relating to generational changes, conflict and maternal pressures may be exacerbated. Participant CC, for example, reported a change of roles in her household and in the mother-daughter relationship since her daughter's stroke.

It's a reverse of roles. I'm the one who runs into the shop and just gets this and runs out and does that, like your daughter would do. I'm the one who serves her, I'm the one who like really cares for her and makes sure she's got everything.

Participant CC

It has been proposed that neurological events may affect the injured person, caregiver as well as the family system as a whole (Yeates et al, 2010). Gan et al.(2006) and Gan and Schuller (2002) found that family members of brain injured individuals presented with increased distress and that this distress was evident in the family system functioning. The effect of the neurological event on the siblings of neurologically impaired persons has been the focus of some studies in recent years (Brown et al, 2004).

Participants JJ, AA and GG described the effects that their adult child's neurological event had on other members of the family. This shows an awareness of the notion that the neurological event does not happen to one person but rather the family system as a whole.

They did everything together... they had the same circle of friends. She battles more now to cope. She's moved on and she's lost her best friends. She loves her brother and she does everything for her brother but there's times when she can only spend a certain amount of time with him because she will then say "it's not (son)".

Participant JJ

Participant JJ described the effect that her son's neurological event had on her daughter, a sibling of a neurologically impaired adult. Again, the cognitive-communicative difficulties resulting from her son's traumatic brain injury are seen as having a negative effect on the relationship between siblings. Participant JJ uses the word "lost" to describe the loss her daughter experienced when her brother sustained a traumatic brain injury. Once again the notion of loss in the family is identified as sequelae of a neurological event. Not only is Participant JJ having to deal with the loss of her healthy adult child, she is also having to support her uninjured daughter as she attempts to cope with the loss of her healthy brother. It may be suggested that this further exacerbates the loss experienced by the parent caregiver.

Our relationship (mother and daughter) is only starting to get better. It's taken its toll on our relationship cos she feels I took more attention to (son). She hasn't sort of understood the fact that we had to pay all this attention to (son) to get him back to normal cos she feels it wasn't her fault.

Participant AA

Similarly, Participant AA identified the negative effects that her son's brain injury had on her uninjured daughter and their relationships. A study conducted by Hutton and Caron (2005) identified jealousy related to time devoted to the injured sibling as an emotion demonstrated by uninjured siblings. The study investigated reactions of non-

disabled children to their siblings with autism and it was found that significant distress was experienced by the unaffected sibling, particularly related to communication difficulties between the siblings as well as perceptions of the parents favouring the autistic child over the other child.

The children don't always respect her quite.. because she's now aunty who's a bit funny, you know. They love her but they don't always give her the respect that she feels that she's due.

Participant GG

Not only did immediate family members appear to be affected by another family member's brain injury or stroke but extended family roles also appeared to be negatively affected by the neurological event, as described by Participant GG above. From this quote it is suggested that the parent caregiver may act as a buffer between the younger children in the family and the neurologically impaired aunt.

When considering the impact that a neurological event has on a family system, it is important that families are counselled regarding the possible role changes that may occur after a brain injury or stroke. Whilst from this and other studies it is clear that role changes within the structure of the family occur, it may be suggested that other roles ascribed to the adult parents are the focus of some resistance by other family members. Clinicians need to be aware of the effect that these role changes and possible resistance to these role changes have on the family system and ultimately the rehabilitation process. Maitz and Sachs (1995) propose that “when families have

difficulty relinquishing their traditional roles and styles of communication, the rehabilitation process can be affected” (p. 9).

4.3. Caregivers’ Fear

Further to the theme of loss, was that of fear. The theme of fear was divided into two subthemes, these being fear of the future and the caregivers’ fears related to caring for the injured adult child.

4.3.1. Fear of the future

I don’t think I would’ve wanted to know what the future holds. Otherwise I don’t think I would, would want to go forward.

Participant BB

We don’t know what the future holds for us...I worry a lot about her and the future.

Participant II

Such feelings of uncertainty and fear of what the future may hold, as described by all of the participants are therefore unsurprising. The quote above suggests that for Participants BB and II, attempting to predict what would happen in the future appeared to be a daunting and overwhelming task. In combination with, or possibly as a result of, the losses experienced by participants and as described in the previous section, the theme of fear is also evident in the narratives of participants.

Participant CC reported that she purposefully did not think about the future but chose instead to worry about the present in terms of her child's neurological event.

Not thinking too much about the future because you know now where that's going to go... and just coping for where you are.

Participant CC

In a study conducted by Silva-Smith (2007) a similar finding of avoidance of thinking about or making plans for an uncertain future was identified. This is similar to the sentiment described by Participant CC where a focus on the "here and now" seemingly allows for a more pragmatic expenditure of emotional resources and therefore an apparent subjective experienced ability to copy.

A study conducted by Greenwood et al. (2009) suggested that the avoidance shown by caregivers in terms of making plans for the future may be seen as an indication of acceptance of the caregivers' situation as well as reducing the risk of disappointment. Studies conducted by Greenwood et al.(2009) and Coombs (2007) suggest that these feelings of uncertainty are common in the experiences of persons caring for their loved ones who have suffered strokes. They further suggest that these feelings of fear and uncertainty need to be acknowledged by the rehabilitation team when creating programmes to support both the caregivers and the survivors.

All of the participants in the study expressed concern regarding the plans for the future for their adult child, particularly the need for ongoing care once they are no longer able to provide care.

I worry if something happens to us.. because we can't seem him living on his own.

Participant EE

Your biggest worry is what happens to your child when you're not there to look after them. That is a big concern – and to know the right things to do.

Participant GG

These practical concerns, such as the inability for the neurologically impaired child to live independently and care for himself/herself without assistance have been identified in the experiences of parent caregivers of adult children with intellectual and psychiatric disorders (Hubert, 2011; Helmsley et al., 2008). It may be suggested that addressing the practical concerns such as those described by Participants EE and GG as well as developing plans and strategies that may be implemented in the future may alleviate some of the fear and uncertainty experienced by the caregivers (Raver et al., 2011; Greenwood et al., 2009). In circumstances such as these, resources permitting, parents were able to find creative solutions and generate plans that they had not previously contemplated.

One of the participants in the study reported that she and her husband had considered the future needs of her son and that they had started a business in which her son could earn a living once they were no longer able to provide for him.

We've had to start a business and get him trained in something, um, so that he's got a future, we're not going to be around forever.

Participant JJ

Uncertainty appears to be very much part of the caregiving process. Greenwood et al. (2009) suggest that “accepting uncertainty seems to be central to coping day-to-day and to adjusting to caregivers’ altered situations” (p. 1132). It would be interesting to explore further the possible link between uncertainty and fear of the future. This study suggests a link between the caregivers’ uncertainty of what the future may hold and how to deal with it. This may lead to feelings of fear experienced and reported by caregivers interviewed in this study. It must be stated that given the sample size and limited focus of the areas probed, this study does not distinguish between fear and uncertainty on a micro-level nor does it attempt to define these concepts as separate entities. In addition, it does not investigate the various factors that may impact on the caregivers’ experiences of uncertainty and fear. These include socioeconomic factors, individual differences such as the psychology of the caregiver, physical health of the caregiver, premorbid characteristics of both the caregiver and the adult child as well as the functioning of the family system before the neurological event. In addition, it does not take into account gender differences or changes in these feelings of fear and uncertainty over time. A study conducted by Macnamara et al. (1990) suggested that feelings of fear and anxiety increased with time since the stroke. Similarly it does not take into account any symptoms of depression experienced by the caregivers. These are all factors that are suggested to have an impact on the caregivers’ feelings of uncertainty (Andren et al., 2007; Greenwood et al., 2009). Greenwood et al. (2009) reported that “uncertainty is double-edged – it allows caregivers to cling onto hope that with time,

their survivor might make unlikely improvements but at the same time leaves them in limbo” (p. 1131).

4.3.2. Fear regarding caring for the adult child

When comparing the interview transcripts obtained from the caregivers, an interesting phenomenon was identified with regards to the mechanism of injury and parental response. The parents of the adult children who had suffered cerebrovascular accidents all reported that they felt concern regarding the medical needs of their children. This was not the case for the parents whose adult children were involved in motor vehicle accidents.

I do have concerns. I worry sometimes that it could happen again, because if it did happen before, whatever caused it they were never able to find out.

Participant DD

This may be because, unlike in the case of a cerebrovascular accident, there is a defined cause of the motor vehicle accident, for example speeding, reckless driving and drinking and driving. Although there are known risk factors associated with cerebrovascular accidents, all the parents of the young stroke victims reported that there was no known or clear cause for their child’s cerebrovascular accident. It may be suggested that this may contribute to the parent caregivers’ experience of fear for their child – if one is unable to pinpoint the cause of an event, one is unable to prevent it. One is also unable to assign blame whereas having a clearly defined external cause may aid in accepting the causality of the neurological event. In addition, the possibility of another stroke adds to the parent caregivers’ experiences of fear and uncertainty.

I am very frightened that I come across something in her I can't manage. What scares me a lot about (daughter's) situation is that I get faced with something in her health that I can't look after, that I can't sort out for her... I'm always frightened there'll be a time when I can't fix it or get the right person to fix it. That I won't always be able to save her life. It's a big fear.

Participant CC

Studies such as the one conducted by Coombs (2007) suggest that, similarly to the concerns expressed by Participant CC, caregivers may also experience fear and uncertainty regarding the medical needs of their neurologically impaired loved one. Similar results were noted in the current study, particularly highlighted by Participant CC. A study conducted by Simon et al. (2009) suggested that female caregivers, such as Participant CC, were more likely to experience fear regarding caregiving responsibilities in the first year after the neurological event. It is interesting to note that fourteen years later, Participant CC continues to experience fear regarding the possible medical and caregiving needs of her daughter and the possibility of another stroke. This appears to give weight to the findings of Hay et al. (2008) who noted the ongoing care and concern of adult parents for their adult children.

4.4. Sources of support

Analysis of the transcripts revealed that all the participants highlighted the importance of receiving support from family, friends as well as the treating rehabilitation professionals. The theme of support identified in this study may be subdivided into two

sub-themes, that being support of family and friends and then, in many cases, abandonment later in the adult child's recovery process.

4.4.1. Support of family and friends

Three participants reported that apart from emotional support, practical assistance and help from others was lacking. Participants AA and II in particular reported that although they received verbal support from others in their environments, practical assistance was lacking and yet was perceived by them as necessary.

I've got a lot of support from friends and family as far as talking to me.

Participant II

Financially they'd come and help and what have you but he (the father) never gave me physical help and physical help is what I needed with (son) because he was a big strapping guy, you know, and even though he's lost all the weight he's still, it's like a dead weight. You've got to pick him up – I had to shower him, I had to take him to the toilet.

Participant AA

In cases where practical support was forthcoming, the responses of participants were more positive. Participant JJ, as did Participant AA, reported experiencing much support and assistance from family friends. Of interest is that Participant JJ reported that despite all the difficulties experienced after her son's accident, she considered it to have had a positive effect on her family.

It's pulled my family together like you won't believe – it made such a strong bond – everybody is there. The family was the biggest helping factor that we could have had that got us through.. and his friends... it's 3 years down the line and they never once ran away from (son) or wouldn't... they come, take him out

Participant JJ

Participant JJ further acknowledged the effect that her son's cognitive-communicative difficulties have on social interactions but that his friends have accepted him despite these difficulties.

It's very hard because you can't take him out in a restaurant and he'll be loud for no reason at all, you know, and it's embarrassing. They are peers, they are young guys... he's not aware of things that he mustn't say, um, he used to blow his friends secrets because he didn't think... but his friends have stayed with him and I think that's helped. That's a support group. We are lucky we had it with the family and friends.

Participant JJ

Participant JJ further comments that her son's friends are seen as an informal "support group" providing both her son and the family system with support. As stated in the introductory chapters, support groups have been identified as playing a vital role in helping family members cope with the effects of a neurological incident (Acorn, 1993). Here the support group is not a professionally run disorder-specific support service, but rather the injured person's friends. As a result it is tailored to meet the specific needs of the injured individual by drawing on the uniquely detailed personal knowledge the "support group members" (friends) have of the injured individual.

4.4.2. Abandonment

Although all participants in this study referred to the support they received from family and friends, particularly in the early stages of their adult child's recovery, many participants also reported that the support did not continue through the recovery process. Sadly, many participants reported an initial sense of support followed by a sense of abandonment, often years after the adult child's neurological event. The loss of friends and social interaction was keenly felt and emphasised in the participants' responses.

She had a busload of friends but they've gone. Absolutely nobody phones her and I mean really, the waiting room at the hospital, they had to stagger and they had to ask them, you know, please just two at a time – like 30 friends all lining the whole waiting room and now, nothing, nothing, nobody.

Participant CC

Participant CC described how her daughter's friends appeared to be very supportive and involved in the initial stages of the recovery but later disappeared. Once again the theme of loss is evident in the caregiver's experience. This now being the loss of the support and company of friends. Unfortunately, in my experience, this is commonly seen in the experience of brain injury and can frequently become a focus of and negatively impact the injured person's progress in the rehabilitation programme.

He (son) sometimes goes out with friends. But, funny, a lot of friends ignore him. They pushed him aside. They disappeared. He was very popular with people.

Participant AA

He had his friends and his girlfriend, you know, he used to only come home to eat and then he was gone again. Came home just to eat and sleep.

Participant HH

In both of these quotes, the adult child's altered participation in social activities, i.e. the life before the brain injury is being compared to the life after the brain injury thereby signifying a loss. Participants AA and HH show a new dimension, one which is characterised by the adult child's visibility within the home and social circles. Initially (pre-neurological event) the adult child is to all intents and purposes visible to the social circle but invisible to the family. After the neurological event, however, the inverse is true. The adult child appears to be invisible to his or her social circle but is sharply visible to his family. It is this stark visibility of the adult child in the home that appears to cause distress for the parent caregivers.

Analysis of the interviews suggested that the parents attempted to justify and explain why their adult child's friends had abandoned the injured person. Participant HH attributed the loss of friends to a lack of understanding on the part of her son's friends. Once again the cognitive-communicative deficits that resulted from her son's brain injury are identified as having a negative effect on his ability to form and sustain social relationships.

They do not understand that he has changed, that he has a problem. They don't understand it and that's why his friends have disappeared. You can understand it from their point of view. You can't blame them. You don't know what you'd do in this situation.

Participant HH

In addition, she further explained that she felt that her son's social isolation was due to his inability to initiate and maintain social interactions and relationships.

He won't just think of phoning someone. If he phones it's to tell us not to forget to fetch him

Participant HH

This lack of initiation, particularly in social relationships, is frequently reported following a traumatic brain injury (Ponsford, 2011).

Listening to the stories of the participants it became apparent that loss was not restricted to family or friends alone. Both parent caregivers and the adult children may experience feelings of loss when a formal caregiver resigns or is replaced by another caregiver. In South Africa, many families rely on nursing agencies to provide them with adequately trained caregivers, depending on the caregiving needs of the injured person. As the contracts are between the responsible family member and the agency and not the formal caregiver, the selection of the caregiver often is made by the agency and is very often dependent on factors that have little to do with the injured person.

This includes transport, working rates and the amount of caregiving that the agency representative deems necessary for the injured person. Very seldom are the relationships between the family members, injured persons and the formal caregivers even considered. This often results in a high turnover of caregivers. In addition, it may be suggested that trust and bonding between the family members, injured person and the formal caregivers may not be optimal due to the unpredictability of caregiver placement.

All the helpers I had, such a change of helpers over time and also that was one thing that depressed her because she just said “ooh all these people are rejecting me, they come here for a month and they go and they can’t stand me” type of thing.

Participant FF

It is interesting to note that Participant FF described how her daughter experienced feelings of rejection as a result of professional caregivers leaving. This may be suggested to further impact on the injured child’s feelings of social isolation and abandonment.

4.5. The need for appropriate information at the appropriate time

It is widely recognised in the studies investigating caregivers’ needs that the burdens faced by both formal and informal caregivers are significant and long-term (Kosciulek, 1995; Kreutzer et al, 2009). A study conducted by Lynch et al.(2008) suggested that

key themes identified in the long-term experiences of caregivers included the need for social support, appropriate coping mechanisms, communication strategies, assistance with physical limitations and increasing the independence of the cared-for individual. In my opinion, these themes identified by Lynch (2008) may centre on the caregivers' need to receive and understand information regarding their child's neurological event.

Please show me a book that we can learn from.

Participant HH

A lack of relevant and useful information regarding their adult child's neurological event was highlighted by all the parent caregivers interviewed in this study. Interestingly most of the adult children were married or in serious relationships at the time of the injury or stroke. During the completion of the biographical questionnaires, it was reported that in these instances the spouses and partners of the injured persons had subsequently left the relationships with the injured persons and the onus for caregiving had fallen on the parents. It may be suggested that the parents of the adult child were not included in the initial information-giving interactions with healthcare professionals as the next of kin were possibly a spouse or partner. These parents, due to the change in circumstances, were possibly not given the right information during the acute phase of recovery which may have aided their understanding of the long-term effects of the neurological event on their adult child.

Where can you find information about what you can do in such a case? I still don't know.

Participant HH

As described in the introductory chapters, the onset of the neurological incident is frequently sudden and does not allow families to prepare for the immediate and more long-term consequences of the neurological event. This was noted in the information provided by Participant JJ. She noted that a lack of appropriate information from the medical staff following the neurological event did not prepare her for the future rehabilitation needs of her son.

We weren't prepared for what we got. We thought we will get that back. But when we left the hospital nobody said "well you're going to need this or this and this".

Participant JJ

All the participants interviewed in this study reported that they were not given sufficient information regarding their adult child's neurological event. This lack of information related to practical advice, equipment needs, necessary home adjustments as well as the changes related to the physical and cognitive-communicative skills of their adult child. The participants in this study described how this lack of information made them feel unprepared for the caregiving needs of their adult child. Because of the lack of information provided by the treating medical professionals, many of the participants reported that they had to gain their own information regarding their adult child's neurological event.

Thanks to the internet. I did a lot of research. I went in because I couldn't understand things. You go out there and you find the information, you know, if he's doing something then I will go and look it up and try and find out something why it's actually happening, you know, that's what makes me understand (son) better and I can deal with him then because I know.

Participant JJ

Participant JJ in the quote above comments on a phenomenon noted by many healthcare workers in society today. In my experience as in the examples described by the participants in this study, the internet is frequently used as a way for families and caregivers to obtain information regarding the diagnosis and subsequent management of a neurological incident. Participant JJ reported that she frequently made use of the internet to interpret her son's behaviour following his TBI. She stated that because of the information gained from sources on the internet, she felt better equipped to deal with the changes in her adult child following the TBI. Unfortunately, the accuracy and the relevance of the information she gained from such internet searches are unknown.

We were told so many bad things, we were given no hope – nothing at all, and we were very sad, but he was determined to, you know, makes things right, that he was very strong willed.

Participant LL

Participant LL commented that she felt the feedback regarding her son's condition was unnecessarily negative and that her son had made a good recovery since his traumatic brain injury. In the quote above, one almost gets the feeling that her son was able to prove the medical specialists wrong due to his "strong will".

I would like to know more about (daughter) and the brain – what exactly is going on in the brain, that's why I have taken her back to the specialist if he can remember – what is going on in her head... how bad is the damage.

Participant II

Another issue highlighted in this study was that parent caregivers may require information and guidance long after the initial injury or neurological event. The need for relevant updates and follow-ups with medical professionals appear to be important for parent caregivers. Of interest is that Participant II's daughter sustained two cerebrovascular accidents approximately fourteen years ago. Despite the lengthy passage of time since the strokes, as well as intensive rehabilitation and contact with many healthcare professionals, Participant II continues to show an interest in aspects relating to the strokes, such as the extent of the damage and the recovery process.

In the study conducted by Smith et al. (2008) it was noted that significant age-related differences existed with regards to the need for appropriate information regarding their loved ones neurological event. The younger caregivers were reported to be more proactive than their older counterparts and made use of the Internet or other resources to gain information. The older caregivers, such as those in this study, were less likely to seek information on their own. The participants in the current study, however, showed a keen interest in increasing their knowledge of their child's condition and ways to cope but appeared to have difficulty in identifying appropriate resources for information.

Participant JJ also described that a lack of appropriate information from the medical staff following the neurological event did not prepare her for the future rehabilitation needs of her son. She further reported that she, unlike the older caregivers in the Smith et al. (2008) study, gained much information from the Internet rather than from medical professionals involved in her son's care. In addition, Participant JJ reported that access to the internet remains a source of information for her too.

You go out there and you find the information, you know, if he's doing something then I will go and look it up and try and find out something why it's actually happening, you know, that's what makes me understand (son) better and I can deal with him then because I know.

Participant JJ

Therapists in the multidisciplinary team were identified as a source of information rather than the specialists and medical doctors. Both Participant JJ and Participant GG reported that they found their dealings with the neurorehabilitation therapists to be beneficial not only in terms of the rehabilitation their adult child received but the parent caregivers experienced the therapists as valuable sources of information. This finding is similar to Smith et al. (2008).

If it wasn't for the therapists that we went to we would have known what to do.

Participant JJ

We didn't get any practical advice – we actually didn't get any advice until we found from this one and that one – various therapists. Once we got in touch with the therapists, then it flowed much easier and we got information on where to go and what to do.

Participant GG

The parent caregivers interviewed in this study expressed a desire and an urgent need to understand both the neurological pathology that has affected their injured child as well as the recovery process. Furthermore, it is important that healthcare professionals

working with families ensure that family members understand the information given to them during both the acute and rehabilitation stages of recovery (Falk, 2009).

I would like to know more about (daughter) and the brain – what exactly is going on in the brain, that's why I have taken her back to the specialist if he can remember – what is going on in her head... how bad is the damage.

Participant II

Participant II reported that she still wanted information regarding the mechanisms of her daughter's stroke and the consequences of the stroke. In addition, she described her need to understand the severity of the brain damage that her daughter sustained. She also reported an interest in her daughter's experience of the stroke.

Analysis of the four major themes and the various sub-themes identified in the interview transcripts suggest that caring for a neurologically impaired adult child in the South African context is a complex and emotionally charged experience. The parent caregivers' provided rare insights into their personal experiences regarding caring for their once-independent adult child. These experiences are discussed in the next chapter.

CHAPTER FIVE

5. Discussion of the results

5.1. Introduction

Upon reflection of the results obtained in this study, it is evident that parent caregivers of adult children who have suffered neurological incidents experience specific reactions both to the incident and the resultant need to care for their child.

5.2. Indefinite loss

The theme of loss resonated through all eighteen of the participants' interview transcripts. The loss described related specifically to the loss of the parents' dreams and plans, the loss of the healthy adult child due to physical and cognitive-communicative difficulties and the loss and subsequent restructuring and reallocation of roles within the intergenerational family. In order to experience a sense of loss, one needs to differentiate between the "before" and "after". All participants clearly reported that their adult child had undergone both significant physical and cognitive-communicative changes since the neurological event. This is in keeping with the literature describing the neurological sequelae of a brain injury and or cerebrovascular accident (Hartley, 1995; Hartley and Griffith, 1989; Hopper and Bayles, 2008; Myers and Blake, 2008; Peach 2008; Stewart and Riedel, 2011; Wambaugh and Shuster, 2008; Ylvisaker et al, 2008;).

This study illustrates that the challenges and concerns expressed by the parent caregivers regarding caring for their neurologically impaired adult child are great and require continuous assessment and intervention from the multidisciplinary rehabilitation team. In addition, this study shows that the parent caregivers' experiences may be likened to that of a grief experience. As discussed in Chapter Two the mourning period is, however, indefinite. This is because the loss of the once healthy adult child is indefinite. Because of this it may be suggested that the support they require both from medical professionals and others in their social support system may be indefinite.

When considering the notion of loss, it is suggested that the loss experienced by the parent caregiver may be somewhat of a linear process, starting with the adult child's initial loss of the premorbid physical, cognitive and communicative abilities. Because of the loss of these abilities and the nature of the physical and cognitive-communicative disorders following a neurological event, the adult child may no longer be able to fulfil his or her premorbid responsibilities. These responsibilities and roles may relate to being a spouse, parent, financial provider and support for the ageing parents.

In addition, this study suggests that the adult parents experience a loss of the quality and nature of the relationship that they would have with the adult child were it not for the neurological event. Because the adult child is unable to fulfil the different roles he or she fulfilled before the neurological event, the parent caregivers assume these roles in an effort to assist their neurologically impaired child. This reallocation of roles together with a reduction in independence and ability to participate in activities of daily living,

result in a loss of the parent caregivers' plans for their future. This is largely due to an increased demand on their time for caregiving.

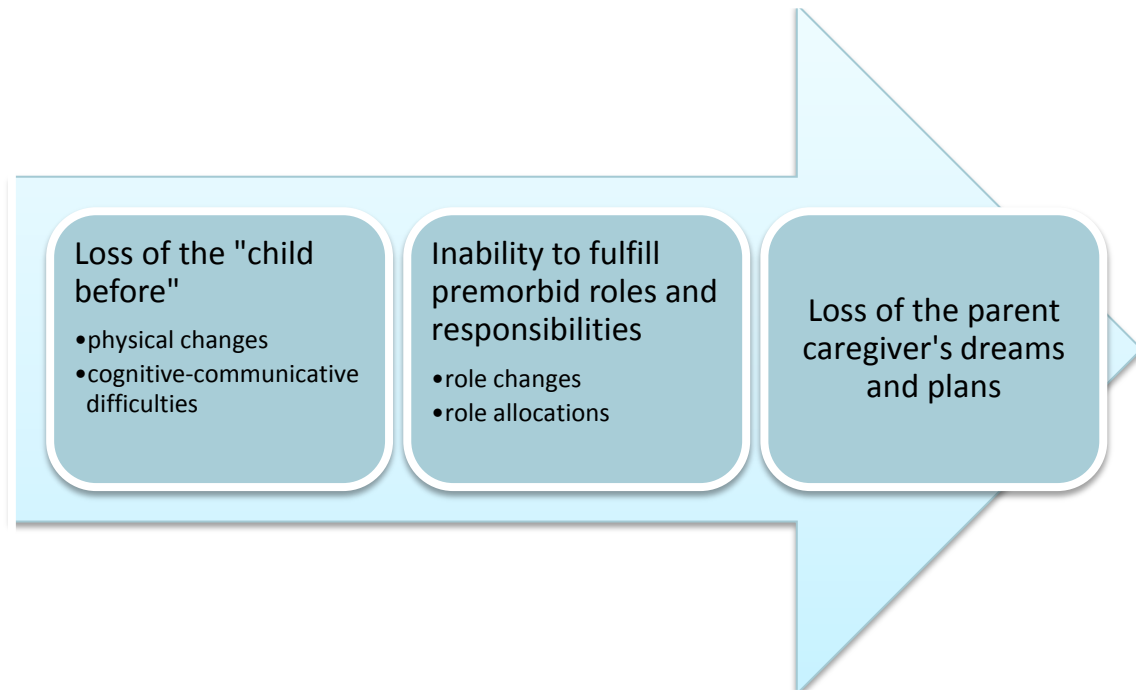


Figure Two: The Progression of Loss.

When considering these findings within a Family Systems Theory framework, I posit that it is this initial loss of the healthy adult child that results in the need for role changes and reallocation. This initial loss may result from the psychosocial type of illness proposed by Rolland (1999) and discussed in Chapter Two. The acute onset of the neurological event and resultant sequelae may be suggested to result in significant stress for the family members. This stress is then magnified when the family member is required to assume different roles within the family, such as a grandparent assuming the role of a parent due to their adult child's neurological incident.

The changes and adaptations that the parent caregivers are required to make in their own lives in order to accommodate the needs of their neurologically impaired child result in further loss - the loss of the parent caregivers' dreams and plans.

As discussed in earlier chapters, the loss of dreams and plans reported by the parent caregivers in this study is not unique to parents of adult children who have acquired brain damage. Kropf and Kelly (1995) suggest that parents of adult children with developmental disabilities such as Down Syndrome, as well as those whose adult children suffer from psychiatric disorders experience similar feelings of loss. In certain psychiatric conditions as well as neurological conditions, the adult child's social behavioural difficulties may result in embarrassment for their parents. This may then pose a limitation or restriction on social and leisure activities which may contribute to the social isolation reported in this study.

Similarly the loss that parent caregivers feel for their child's premorbid personality in both acquired brain damage and psychiatric conditions may further add to their grief. Studies have shown that parent caregivers report feelings of grief when considering the quality of their relationship with their adult children (Kropf & Kelly, 1995). As stated earlier, the cognitive-communicative difficulties that occur as a result of a neurological event may negatively impact on the parent-child relationship. It is suggested that parents may undergo a process of "wishful thinking" in which they may imagine how the relationship could be if the neurological event did not occur. This may further add to their experience of loss.

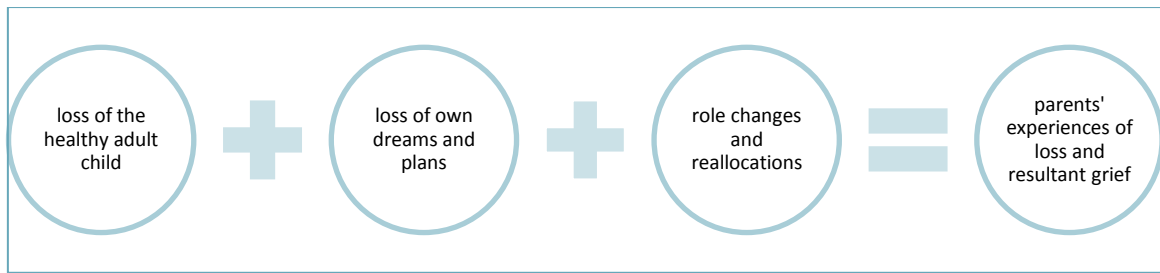


Figure Three: Compounding loss resulting in the parent caregivers' experiences of loss and resultant grief.

5.3. Changes within the family system

As discussed in Chapter Two, changes within the family system are common following a neurological event. The physical, cognitive and communicative deficits that result from the neurological event, often necessitate changes and accommodations within the family system (Rolland, 1999). These roles changes and reallocations, although necessary, may further add to the parent caregivers' experience of loss.

As noted in the analysis of the interview transcripts analysed in this study, role changes within the family are common following a neurological event such as a brain injury or stroke (Natterlund, 2010; Wallengren et al., 2008). Family therapists suggest that it is vital for the therapist involved with families who have been affected by brain injuries to gain an understanding of the pre-injury roles including the distribution of power and authority (Laroi, 2003).

Laroi (2003) explains that the consequences of the roles changes evident after a brain injury may result in either a re-establishment of roles as they existed before the injury or may necessitate redistribution of roles following the injury due to the injured individual's inability to fulfil his or her pre-injury role in the family. Laroi (2003) further explains that these role changes may specifically affect the parent-child relationship, particularly when the brain injury results in an increased dependency of the parent on the child. Children may need to assume the roles of the parent's caregiver and this would result in a significant change in the communication patterns of the family (Laroi, 2003). Conversely, as in this study, the parent of the adult child may have to reclaim the role and associated responsibilities of caring for an adult child who has suffered a neurological event.

As in the study conducted by Schatz (2007), this study has also highlighted the growing trend of intergenerational families in South Africa, that being more than one generation residing in the same home. The participants in this study reported that they perceived the interaction with their grandchildren in the home as positive. This is similar to a study by Poindexter (2009) that found that grandparents reportedly viewed the decision to raise their grandchildren as positive and saw it as an opportunity for them to remain active, build relationships with their grandchildren while enjoying the companionship of others during their later years (Poindexter, 2007). This finding appears to be seen in other countries and not only within the South African context (Fuentes, et al., 2007; Winston, 2006). Similarly, studies such as those undertaken by Attar-Schwartz et al. (2009) and Attar-Schwartz, Tan, Buchanan, Flouri and Griggs (2009) suggest that an increase in the amount of contact between grandparents and grandchildren has been shown to increase emotional closeness between generations, facilitate the development

of appropriate social behaviour and minimise emotional problems in the younger generation.

An increase in both the quality and quantity of contact between older adults and children has been identified as having potential benefits for both the communication partners and society as a whole (Alexander and Abell, 2010; Hannon and Gueldner, 2007; Pinanzo-Hernandis and Tompkins, 2010). The benefits of increased intergenerational contacts include encouraging caring and nurturing of firstly the child and then the older adult in later years (Hannon & Gueldner, 2007; Shatz, 2007). Exchange of information and continuation of family traditions, customs and values may also be more readily sustained through these intergenerational contacts. In addition, various disciplines such as nursing, education, social work and therapy may also benefit from this increase in amount and quality of intergenerational contacts and may allow for a better understanding of intergenerational communication within specific contexts (Armstrong & McKechnie, 2003; Hannon & Gueldner, 2007). Talking about these issues both intra and intergenerationally may not only highlight the difficulties experienced by different generations but may also allow for better facilitation of communication between generations, thereby contributing to the bridging of the age-old generation gap.

Studies have shown that the structure of the family unit has changed, particularly due to changing demographic and cultural aspects (Celdran, 2010). Conway et al. (2010) suggest that “learning more about family structure and family relationships could enhance identification of families that are at risk and more appropriate methods for

meeting their needs” (p. 141). This sentiment is echoed by Bohman et al. (2009) and Rolland (2005, 1999) who suggest that the extended family may be seen as valuable resources for the affected family system.

5.4. Caregivers’ fears

It is accepted that parents will worry about their children – regardless of the child’s age. Studies such as those cited by Hay et al.(2008) suggest that worry is relatively common in a healthy parent-child relationship. In this study, the worry experienced by the parent caregivers were reported to relate to the adult child’s medical condition. It is suggested that the parent caregivers need to continually identify and manage perpetual symptoms relating to the initial neurological incident. In addition, the prospect of a second incident has been shown in this study to exacerbate the feelings of worry and uncertainty reported by the parent caregivers. Furthermore, the ageing and physical weakening of the parent caregivers and the concern regarding future needs of the adult child further adds to the strain and exhaustion experienced by the parent caregivers.

Some studies have suggested that the parent caregiver’s experience of fear may be linked to the physical and mental health of the child (Beck et al, 2001; Hoyer, Becker and Roth, 2001). The study conducted by Hay and her colleagues suggested that older parents continue to show concern regarding their adult child’s health, safety, relationships and finances.

When considering these issues within the context of the current study, it may be suggested that adult parents may experience worry regarding their child as the neurological event may negatively impact on these aspects of their adult child's life, namely those related to health, safety, relationships and finances. The adult child's inability to independently manage his or her own health, safety, relationships and finances is shown in this study to exacerbate the fear and worry reported by the parents regarding their injured adult child. In addition, it is suggested that the parent caregivers experience difficulties in reconciling the expected life stages, for example retirement, with the family stage, that being the caregiving or even parenting stage. Both the parent caregivers and the injured adult child find themselves in non-chronological unexpected life stage. This may be explained by the model proposed by Rolland (1999) which emphasises the importance of both the individual's life stage and family's life stage. When considering the results from this study, it is suggested that participants viewed this as a regression in terms of their adult child's expected life stage. Once again, this relates to the loss experienced by the parent caregivers.

5.5. The right information at the right time

This study illustrates the importance of the right amount and type of information at the right time. It is suggested that access to appropriate information and services, particularly regarding the long-term caregiving needs, may reduce the fear experience by the parent caregivers. The need for information-giving must not be ignored in favour of the therapy programme and focus on the injured individual. Laroi (2003) explains that families need to be educated and reminded that many of the problems experienced by the individual and that family are physiological. This implies a process that takes

place over a long period of time, not merely in the acute phase of recovery. Adequate information given to family caregivers at the appropriate time may be suggested to minimise the risk of personalising the behaviour and perhaps even preventing the person with the brain injury from becoming the scapegoat (Gan et al., 2006). Laroi (2003) cautions, however, that therapists working with families must be aware of the different reactions – “those reactions that can be expected as a result of the brain injury, those that cannot be directly attributed to the brain injury but can be seen as normal reactions to the event, and finally reactions which are not related to the injury at all” (p. 177). In addition, attention must be given to the communication environment in which the communication disorder exists – “if the communication environment is filled with tension or distress, then optimum communication may not be achieved and there could be a decrease in the level of communication effectiveness and satisfaction over time” (Threats, 2010, p. 456). This deterioration in communication may not be as a result of the cognitive-communicative difficulties but may occur as a result of tension or distress within the environment. This sentiment was echoed in a studies conducted by Threats (2007) and Baylor, et al. (2011).

Many studies have highlighted the need for families to receive adequate and appropriate information regarding a loved one’s neurological event and the potential consequences of such an event on both the injured individual and the family members (Degeneffe and Olney, 2008; Le Dorze and Signori, 2010; Natterlund, 2010; Wallengren et al., 2008). Studies investigating families perceptions of information provided relating to a young child’s brain injury have shown that parents who received the right information at the right time were found to experience less anxiety (Falk et al, 2009). These well-informed parents were also found to be more prepared regarding the possible effects of

the child's head injury on both the child and the family. This was noted as having a positive effect on the child's level of stress and positively impacted on the child's recovery process (Falk et al, 2009). The current study suggests that parents of adult children who have suffered neurological events such as brain injuries, may also benefit from receiving appropriate information and counselling during the initial stages of recovery.

As the old saying goes, "timing is everything". Many studies have highlighted the need for caregivers to receive appropriate information at the appropriate time during the recovery process (Cecil et al, 2011; Smith et al, 2008). In my professional experience and based on the interviews analysed it may be suggested that the presentation of information may not always be correctly timed according to the needs and acceptance process of the parent caregivers. One cannot forget that to the parent caregivers the injured adult child is still their child and any information regarding the injured child's recovery and prognosis may elicit an emotional reaction within the parents.

It may be suggested that information needs to be made available to parent caregivers at any point during the adult child's recovery process. It is suggested that this may be achieved through the use of support groups and multimedia resources, such as the internet, books, brochures and workshops.

5.5.1. The need for practical caregiver training.

The participants in this study expressed their need for practical training from the healthcare professionals, an idea echoed in studies such as that conducted by Cecil et al. (2011) and Falk (2009). It is suggested that, particularly in the South African contexts, issues regarding discharge from acute or rehabilitation settings are frequently rushed due to financial and other resource constraints. This trend has been noted internationally and, according to Kreutzer et al. (2009), “shortened hospital stays necessitate a greater in-hospital focus on physical and functional goals and fewer opportunities for rehabilitation staff to address the full spectrum of survivors’ and family members’ needs” (p. 535).

All too frequently informal or family caregivers are not provided with the correct training in order to manage the physical, cognitive-communicative and emotional challenges faced by both the injured person and the family caregivers. In addition, it is suggested that the early discharge from healthcare settings may allow the injured person and the family members little time to process their emotional reactions to the initial injury (Kreutzer et al., 2009). Health professionals need to offer and facilitate both practical training and “trouble-shooting” opportunities in which the caregiver, injured person and health professionals are actively involved.

5.5.2. The internet as a source of information for parent caregivers

This study suggests that parent caregivers need information and are becoming increasingly more assertive in their requests for information regarding their loved one’s

medical condition, treatment options and rehabilitation plans. According to Alexander and Abell (2010) the appreciation and understanding of how science has impacted on society varies between societies, cultures and generations. Stereotypically, older people are often seen as reluctant to make use of high-tech devices. This, however, was not noted in this study. The older caregivers showed a keen interest in using the internet as a source of information regarding their adult child's neurological evident and subsequent difficulties.

The use of the internet as a source of information for parent caregivers was highlighted in this study. This mirrors a trend that I have noted in practice as well as one that has been discussed in both informal and academic medical articles. Escarrabell et al.(2011) explain that increasingly healthcare consumers are utilising the internet as a source for the diagnosis and management of health ailments. This is suggested to be due to the relative ease and speed at which information can be gained. In addition, when consulting internet webpages for information regarding a health complaint, it is not necessary for the consumer to be in the same place as the healthcare provider thereby making access to the information easier. The advantages of ease of access and availability have been acknowledged within the medical fraternity (Tang & Ng, 2006).

There are, however, concerns regarding healthcare consumers using the internet as an alternative to consulting with medical professionals. Tang and Ng (2006) found that the internet was more effective in diagnosing and providing management options for conditions with unique symptoms and signs. They caution that for more complex disorders with a wide range of symptoms, the internet may not be useful in providing

helpful information. When considering the wide range of symptoms that may be evident after a neurological event, it is suggested that the internet should be used with caution as a means of gaining information regarding TBIs and strokes. It is my opinion that therapists involved in neurorehabilitation need to be familiar with and provide family caregivers with information regarding accurate and helpful sites that contain accurate information regarding neurological events and caregiving needs.

In a country like South Africa, the internet may not be accessible to the majority of caregivers. According to the South African Yearbook (2010/2011) approximately only 10 % of the population has access to the internet. Furthermore Bohman et al. (2009) caution that the impact of modernisation may fast be increasing the generation gap. A reason for this may be that technology is not as readily available to older adults. Once again, it appears that current world trends such as the use of the internet as a means of communication may not be representative of the situation in South Africa.

5.5.3. Facilitating good communication between caregivers and healthcare professionals

This study also identifies the communication difficulties that can occur between family members and medical staff. Many of these difficulties appeared to relate to a scarcity of information provided by the medical professionals. These are similar to the difficulties identified in the literature (Azoulay et al., 2000; Bandeira, et al., 2011). In a multilingual-multicultural country such as South Africa, it may be suggested that many of these difficulties may arise or be compounded by language and cultural differences

between these two parties. In addition, expectations particularly regarding the amount and type of information required by family caregivers may differ significantly and therefore, these expectations need to be discussed and evaluated during interactions.

It may be suggested that the path of information required is a two-way street. Healthcare professionals working with families who have been affected by a neurological event also need to gain information about both the caregiver and the injured individual. Cecil et al. (2011) emphasise that it is important to understand “what caregivers want to do, and expect to do, for the care-recipient” (p. 1723). Awareness of the needs, expectations and goals of the caregiver are important in developing appropriate therapy plans and interventions. Particularly when considering an ecosystemic framework, it is vital for the healthcare professional to gather information regarding the family’s structure, family members’ roles and an idea of how the family system functioned both before and after the incident (Yeates et al., 2010). In addition, in my opinion, therapy plans that are specifically tailored to meet the needs of an individual client and their family members, needs to be based on information gleaned from family members both in the initial interview and during the rehabilitation process. Families are made up of dynamic, changing human beings. It is imperative that therapists are aware of the changes that occur in the individuals involved in the therapy process and the effect that these changes have on the family system as a whole.

It is vital that both the caregivers and relevant health professionals are able to work towards the same goal in the rehabilitation of the injured individual. It is suggested that this can only happen if the communication lines between both the caregivers and health

professionals remain open. Smith et al. (2008) suggest that “family caregivers are integral part of the rehabilitation team, and yet there is no consistent approach to support or involve them in the rehabilitation process. This may be partially due to the limited availability of information concerning caregivers’ specific support needs during this time” (p. 594).

5.6. Similarities in familial caregiving experiences

Many studies have investigated the long-term needs of spouses of individuals who have suffered brain injuries and strokes (Anderson et al., 2002; Le Dorze and Signori, 2010; Natterlund, 2010). This study suggests that the experiences and needs of spouses and those of parents of adult children who have suffered neurological events may be similar. These needs arise from the changes in the couple’s relationship, particularly due to changes in communication patterns, roles and responsibilities within the family (Le Dorze & Brassard, 1995). This study shows that changes in the communication patterns, roles and responsibilities between the parent caregivers and the adult child may result in relationship changes. Studies have shown that “clear and accurate communication between spouses is considered essential in maintaining relationships and is an expected element in marital roles” (Beach and Arias, 1983 and Kahn, 1970 as cited by Joubert et al., 2010, p. 35). Hence a change in communication efficiency, such as dysarthria or aphasia, may be suggested to have a significant effect on the relationship and marital roles as well as the relationship and parent-child roles discussed in this study. Furthermore, Threats (2010) suggests that the spouse of the impaired individual can be viewed as the “hidden victim” and may be the most important and or

willing communication partner. This idea is echoed in the study conducted by Wallengren et al. (2008).

These findings are similar to the findings in this study. In this study the parent caregiver may be seen as the “hidden victim” following their adult child’s neurological event. It is evident from the transcripts that all the participants in this study reported that the cognitive-communicative difficulties demonstrated by their neurologically impaired adult child had a negative effect on their interactions and subsequently their parent-child relationship.

It has been suggested by authors such as Casado et al. (2010) that the appointment of formal paid caregivers may offer respite for the burdened familial caregivers. Studies have shown that formal caregivers may be involved in providing medical and physical assistance as well as assisting in decision-making together with the family of the care recipient (Sims-Gould & Martin-Matthews, 2008). In theory, this appears to be a good idea. The reality is that private caregiver services in South Africa are costly and inaccessible to a large percentage of the population. In addition, as illustrated in this study, caregivers are often transient and may leave once a healthy relationship has been formed between the care recipient and the caregiver. This may result in negative emotional reactions as a sense of abandonment on the part of the injured person and the family as a whole. Alternatively, the paid caregiver may be seen as part of the family and may provide assistance which falls outside of their professional duties (Sims-Gould & Martin-Matthews, 2008). This may place both the injured person and the formal caregiver at risk.

5.7. Implications of this study

The results of this study may be suggested to have implications for Speech and Language Therapists as well as other healthcare professionals working within the field of Neurorehabilitation. In addition, implications for further research as well as implications for policy makers are discussed below.

5.7.1. Implications for Speech and Language Therapists working within the field of Neurorehabilitation

Speech and Language Therapists are trained to assess and manage a wide range of both developmental and acquired communication difficulties. In the rehabilitation team, it is the Speech and Language Therapist who is best equipped to manage not only the communication difficulties identified in neurologically impaired patients, but I propose, that as communication specialists, we have a unique role to play in facilitating appropriate and efficient communication between the rehabilitation team and the neurologically affected family.

Speech and Language Therapists need to embrace the role of communication specialists in order to facilitate improved teamwork within multidisciplinary teams as well as improved carryover of information from the rehabilitation team to the family of the neurologically impaired person. It is also our duty to facilitate improved communication between the neurologically impaired person and the rehabilitation team. This should be based on our knowledge of the cognitive-communicative difficulties that can occur after a neurological event as well as the therapy interventions and

conversation facilitators that can be implemented in order to improve communication and understanding between individuals. This may further positively impact on positive therapy outcomes for both the injured individual and the family as a whole.

5.7.2. Implications for health professionals working within the field of Neurorehabilitation field in South Africa

This study highlights the need for specific programmes to address the fears and unmet needs of the parents residing with and looking after their neurologically-impaired adult children. These programmes should not only identify problems faced by ageing caregivers. Programmes should help older parents recognise ways of coping with the caregiver role and responsibilities. Greenwood et al. (2009) suggest that “identification of the positive aspects of caring may help caregivers manage the challenges and uncertainties” (p. 1122). This needs to involve the input and expertise of the multidisciplinary therapy team.

Rehabilitation therapists need to develop programmes specifically geared to the needs of ageing parents of neurologically impaired adult children. These programmes should include the assessment and management of problems relating to parenting for the second time. Furthermore, healthcare professionals should be involved in awareness campaigns in order to prevent possible difficulties identified in the caregivers’ experiences. This includes the dispensing of the appropriate information at the appropriate time.

In addition, this study identifies the need for family intervention to extend beyond the initial stages of recovery. It has been suggested that the neurologically-impaired individual's progress and reintegration into the community may be maximised when the needs of the family are addressed (Falk-Kessler, 2011). This together with increased social participation of the injured individual may then improve the caregivers' experience. In addition, Griffin et al. (2012) suggest that families may require assistance in planning for long-term care needs. It is suggested that "understanding many of these issues will help to better inform families of policies for benefits and resources and help researchers and clinicians plan for appropriate interventions" (Griffin et al., 2012).

Furthermore, family members may require specific training following a neurological event in the family. This may be due to the roles changes and changes within the family structure identified in this study. This may involve grandmothers undergoing "re-parenting training" when adopting the role of primary caregiver to their grandchildren (Thupayagale-Tshweneagae 2008).

I propose that rehabilitation therapists working with the field of adult neurogenic disorders have an obligation to promote awareness of the high incidence of violence and injury which frequently result in TBIs. In addition, I feel it is our duty to create awareness of the risk factors associated with noncommunicable disease such as cerebrovascular accidents. Neurorehabilitation therapists need to be involved in awareness initiatives that focus on educating individuals and communities about the risk factors associated with cardiovascular disease and stroke. In addition, therapists should

be more aware of initiatives drawing attention to the high incidence of TBIs in South Africa.

Studies have shown that the structure of the family unit has changed, particularly due to changing demographic and cultural aspects (Celdran, 2010). Conway et al. (2010) suggest that therapists working with families need to identify families who are at risk for experiencing difficulties relating to caregiving. In addition, they state that therapists should be involved in the development of appropriate intervention strategies for assisting families who are struggling with issues related to caregiving. This sentiment is echoed by Bohman et al. (2009) who suggest that “it is necessary for the care profession to expand the concept of what constitutes a family and not only restrict it to the traditional western nuclear family model as acknowledge the extended family as a care resource in our multi-cultural and multi-ethnic societies (p. 453). Talking about these issues both intra and intergenerationally may not only highlight the difficulties experienced by different generations but may also allow for better facilitation of communication between generations, particularly in intergenerational families affected by neurological events.

5.7.3. Implications for further research

Research into the experience of caregiving and the effects of cognitive-communicative difficulties on intergenerational families such as in the South African context is, however, lacking. In addition, the ways in which different cultures in South Africa perceive the effects of neurogenic communication disorders in family systems also

requires further investigation. Such investigations would facilitate the development of culturally appropriate therapy programmes for neurogenic communication difficulties – approaches that are lacking in South Africa at present (Wasserman, De Villiers and Bryer, 2009). These pose interesting research topics for speech and language therapists in South Africa today.

Upon reflection of the results of this study, there are many aspects of the caregivers' experience of parenting for the second time that need to be further investigated. This study did not investigate the changing needs of both the parent caregiver and the adult child as they both age. There is a need to investigate the changes in the experiences of both parties and the needs they both face over time. In addition, this may help rehabilitation therapists and family members predict and prevent possible difficulties in the long-term caregiving experience.

There is also a need to investigate the experiences and perspectives of the adult child. Studies need to investigate the specific challenges these adult children face when being integrated back into their parents' home following a neurological event. In addition, it would be helpful to identify difficulties associated with role changes and reallocations from the point-of-view of the adult child in order to allow a smooth transition to the new family structure.

Intergenerational communication in South Africa warrants more research, particularly focusing on the differences in the types of communication systems used across cultures

and languages. In addition, care professionals would benefit from an increased awareness of not only the intergenerational needs of communities but also specific intergeneration communication styles. This would allow for the development of supportive programmes and interventions in order to maximise the well-being and experience of intergenerational families (Bailey et al., 2009).

Research regarding the similarities and differences of parent caregivers' experiences caring for their adult children with other chronic conditions such as HIV/AIDS in the South African context is lacking. It is suggested that the challenges experienced by the parent caregivers in this study may be similar to those of parent caregivers providing care for their adult children suffering from HIV/AIDS.

It may be beneficial to both researchers and rehabilitation therapists to compare the needs and challenges faced by familial and informal caregivers following a neurological event. Comparisons of the caregiving experiences of spouses, parent caregivers, siblings and child caregivers may yield common themes and challenges which may help identify the need for and development of programmes that may incorporate intervention for the family as a whole.

It is widely recognised that burden on informal caregivers is great. It is suggested that the normal ageing process and the changes that accompany it may further negatively impact on the quality of life of informal caregivers. Further research into this suggestion is recommended.

Once such programmes have been implemented, there is a need for longitudinal studies to investigate the effectiveness of the programmes suggested in this research.

5.7.4. Implications for policy makers

Currently in South Africa, a parent caregiver or primary caregiver of a child with a disability is entitled to a childcare grant of R1270 per month. This is based on a medical examination by a state medical officer that deems the child in need of full-time and special care. According to the South African Government Services' website, the benefit of the grant is not available to parents caring for a child over the age of 18 years. Once a child is over 18 years of age, there is a need to apply for a separate disability grant. Obtaining this grant involves a lengthy application process and may be refused under certain conditions. To my knowledge, there is no grant available to parent caregivers of adult children requiring full-time and special care. It is suggested that policy makers consider the financial plight of these older parent caregivers whose only income is, very often, the state old age pension of R1270. Special adult childcare grants need to be considered in order to ease the financial burden faced by these parent caregivers.

Given the high incidence of migrant labourers in South Africa, as described in the introduction of this dissertation, policy makers need to consider the financial difficulties faced by non-South African aged parents caring for their adult child whilst working in South Africa. This is a contentious issue to say the least.

As stated earlier, Speech and Language Therapists possess unique skills and expertise necessary to assess and manage a range of acquired and congenital communication disorders. It is hoped that relevant policy makers will continue the trend of increasing the number of posts available for qualified Speech Therapists and Audiologists, particularly in rural areas and in light of an increasing incidence of injuries and diseases associated with cognitive-communicative disorders.

In accordance with the National Health Insurance service delivery model, Speech and Language Therapists need to be involved in forming and sustaining public-private partnerships in order to allow rehabilitation services to be accessible to all South Africans.

The role that policy makers can play in easing the burden of familial caregivers in South Africa has not yet been properly defined. However, assisting families meet their immediate financial obligations and providing them with accessible resources for support and education is a good start. Sims-Gould & Martin-Matthews (2008) state that policy makers need to be aware of the challenges faced by familial caregivers. They suggest that focus needs to be placed on increasing governmental support for caregivers whilst developing appropriate policies to assist familial caregivers.

CHAPTER SIX

6.1. Limitations of the current study

The aim of this study was to investigate the experiences and challenges of a group of parent caregivers who have resumed the role of caregiver for their neurologically impaired child. The results of this dissertation are based on a relatively few interviews from a limited context. In addition, the participants were drawn from the same geographical area. The findings of this study within these contexts, therefore, limit the capacity for generalisation across the South African context.

In addition, purposive sampling was utilised in order to target participants who met specific inclusion criteria. Participants were recruited from support groups and through therapy centres. It may be suggested that the individuals selected for this study may be more motivated or involved in their adult child's caregiving and rehabilitation programmes than other parents who do not make use of support groups or rehabilitation services. In addition, the study did not account for or attempt to include parent caregivers who were unable to access the support group or rehabilitation services offered.

Furthermore, the sample is not representative of the racial and language diversity found in South Africa. It is suggested that a larger study incorporating a wider range of language and racial groups is necessary.

Of the twelve participants interviewed, six were admitted for inpatient rehabilitation following the neurological event. It may be suggested that, given the well-known discrepancies between the “haves and have-nots” in terms of private and public healthcare, this sample may not be representative of the South African population requiring inpatient rehabilitation services. A larger, more heterogeneous sample is needed in order to generalise the results of this study.

Gender differences regarding the mothers’ and fathers’ perceptions of the change in the injured adult child and the change in the parent-child relationship were not investigated in this study. Studies have shown that the parent gender may influence the perceptions of change and relationships with sons and daughters (Proulx & Helms, 2008).

Objective measures, such as neuropsychological tests were not administered to identify the exact nature and severity of the cognitive-communicative difficulties reported by the parents of the neurologically impaired adult children. The researcher merely relied on the parent caregivers’ perceptions of their adult child’s cognitive-communicative difficulties. This implies that the sample may not be accurately matched in terms of the severity and type of behaviour, cognitive and communication deficits reported by the parents.

There is a lack of pre-injury measures of the family functioning. Klonoff et al. (2006) conducted a study to investigate the pre-injury variables related to post-discharge psychosocial status. This study suggested that the injured person’s premorbid

psychosocial functioning provided an important context for understanding the rehabilitation outcome. The researcher relied on the reports of the parents of the adult children. One, therefore, cannot assume that the changes in the family system are directly related to the adult child's neurological event. Clinically, however, one can expect that the cognitive-communicative difficulties and the neurobehavioural symptoms of the neurological event may have a negative effect on the family system.

6.2. Conclusion

“If Schumacher survives he will not be Schumacher. He will be (Mr.) Bloggs.

And his rehabilitation will only be effective if he comes to terms with being Bloggs –
and fulfils what Bloggs can do.”

Richard Greenwood, Consultant Neurologist (January 2014)

Homerton Hospital

This quote published after the recent tragic accident that left Formula One driver Michael Schumacher with severe head injuries, encapsulates the idea that neurological incidents result in a loss of the person before. Not only does the survivor need to come to terms with the new self and resultant abilities and disabilities, this study has shown that the family members, particularly the parent caregivers, experience a loss of their once healthy adult child.

This study suggests that these parent caregivers need to get to know a different adult child – an adult child that has changed physically, cognitively and who often communicates with them in a different way. Because of the link between communication and the establishment of relationships, very often the relationships between the parent caregivers and the adult children change. Role changes may also occur which further adds to the stress experienced by the older parent caregivers. These factors result in an experience of loss similar to the loss experienced by parents of adult children with psychiatric conditions as well as developmental disabilities. The significant difference for the parent caregivers in this study, however, is that the change from a healthy independent adult child to a neurologically impaired adult child occurs suddenly and without warning. It is suggested that the suddenness of the loss may compound the grief and feelings of loss experienced by the parent caregivers.

In addition, these parent caregivers, because of the context in which they and their adult children live, have to deal with practicalities of rehabilitation in a developing country. These realities and difficulties are discussed throughout the study and form the matrix onto which these experiences are formed.

When considering the results from this study in relation to the model proposed by Rolland (1999), it may be suggested that the parent caregivers encountered and continue to encounter many of the challenges put forward by him. These include role allocations, burn-out, fear, lack of information and restricted resources. It may be said that the parent caregivers in this study follow this model by continually adapting during the transition phases thereby facilitating the maintenance of a non-rigid system that allows

for the necessary adaptations to occur (Becvar & Becvar, 2009). In addition, the parent caregivers reallocated and accepted new roles within the family system in order to maintain family system functioning. Furthermore, the parent caregivers' appear to be continually adapting to the developmental challenges faced by the injured adult child, the parent caregivers and the family system as a whole.

This study suggests that the loss experienced by these parent caregivers may be better managed if the appropriate information and support services are in place from the acute stages of rehabilitation. Furthermore, the caregiving experience is infinite. The duration of the need for caregiving is unknown. Most importantly, this study shows that the loss of the healthy adult child as described by the parent caregivers in this study is indefinite.

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APPENDIX ONE:

PARTICIPANT QUESTIONNAIRE

Thank you for your willingness to be a part of this study.

Please answer the following questions. Your responses will be treated confidentially and at no time will names or other personal information be released.

Should you wish to receive a copy of my research report, please fill in the details below.

Name: _____

Postal address: _____

Contact no: _____ (home) _____ (cell)

Email address: _____

Participant Information

Parent / Caregiver 1

Date of birth: ____/____/____ (dd/mm/yyyy) Age: ____

Parent / Caregiver 2

Date of birth: ____/____/____ (dd/mm/yyyy) Age: ____

How long have you been married / living together? _____

Do you have any other family members / persons living with you? ☐ Yes ☐ No

If yes, please list their ages and relationship to you.

Information about your adult child

Date of birth: ____/____/____ (dd/mm/yyyy) Age: ____

Relationship to you: _____

Do you and your child communicate in (please tick the correct box):

☐ English ☐ Afrikaans ☐ isiZulu ☐ Xhosa ☐ Tswana

☐ Northern Sotho ☐ Southern Ndebele ☐ Swazi ☐ Southern Sotho

☐ Tsongo ☐ Venda

Other languages (please specify) _____

What was your child's occupation before the injury?

Did your child work full time or part time before the injury?

Who was your child living with before the injury?

Details of the stroke / aneurysm / head injury

Type of neurological event (tick the appropriate box)

☐ stroke / cerebrovascular accident

☐ traumatic brain injury

☐ brain tumour

☐ aneurysm

Other (please specify) _____

Date of injury: ____/____/____ (dd/mm/yyyy)

Did your child have medical aid at the time of the injury / stroke / aneurysm? ☐ Yes ☐ No

Please specify details of the injury / stroke / aneurysm.

Was your child admitted to a rehabilitation clinic after the incident? ☐ Yes ☐ No

If yes, please indicate which rehabilitation centre

Did you child receive any compensation / disability grant as a result of the injury / stroke / aneurysm? ☐ Yes ☐ No

If yes, please specify _____

Do you or your child belong to a support group? ☐ Yes ☐ No

If yes, please specify _____

Did your child receive any outpatient rehabilitation therapy in the first 2 years after the incident? ☐ Yes ☐ No

If yes, please indicate the type of therapy by ticking the appropriate block:

☐ Physiotherapy ☐ Occupational Therapy ☐ Speech and Language Therapy

☐ Psychologist / counselling ☐ Biokinetics

Other – please specify

Does your child currently receive any outpatient rehabilitation therapy? ☐ Yes ☐ No

If yes, please specify the kind of therapy and how often. Please include any alternative therapies such as Reiki, aromatherapy, acupuncture and reflexology.

How long after the incident did your child come to live with you?

APPENDIX TWO: ETHICS CLEARANCE CERTIFICATE



Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON MEDICAL)
H120806 Sedgwick

CLEARANCE CERTIFICATE

PROTOCOL NUMBER H120806

PROJECT TITLE

Parent Caregivers' Experiences of Caring for their Adult Child in the South African Context.

INVESTIGATOR(S)

Ms R Sedgwick

SCHOOL/DEPARTMENT

Human and Community Development

DATE CONSIDERED

17 August 2012)

DECISION OF THE COMMITTEE

Approved Unconditionally

EXPIRY DATE

31 July 2014

DATE 26 September 2012

CHAIRPERSON

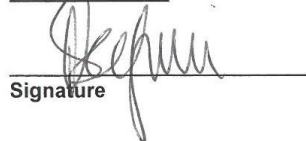

(Professor T Milani)

cc: Prof. C Penn

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to completion of a yearly progress report.**


Signature

08 / 11 / 2012
Date

APPENDIX THREE:

INTERVIEWER QUESTIONNAIRE

Thank you for your willingness to be a part of this study.

Please answer the following questions. Your responses will be treated confidentially and at no time will names or other personal information be released.

Should you wish to receive a copy of my research report, please fill in the details below.

Name: _____

Postal address: _____

Contact no: _____ (h) _____ (cell)

Email address: _____

Interviewer Information

Date of birth: ____/____/____ (dd/mm/yyyy) Age: _____

How long have you been married? _____

Do you have any other family members / persons living with you? ☐ Yes ☐ No

If yes, please list their ages and relationship to you.

What is your home language? _____

Do you speak any other languages? If yes, please specify.

What is your highest level of education? Please tick the appropriate box.

☐ High School (Grade 10) ☐ High School (Grade 11) ☐ High School (Grade 12)

☐ Certificates (please specify) _____

☐ Diplomas (please specify) _____

☐ Degrees (please specify) _____

Employment status: _____

Occupation: _____

Please briefly state relevant counselling experience and training.

**I acknowledge that I _____ have read,
understood and signed the consent forms.**

**I am aware that I will receive financial compensation at a set hourly rate of
R_____.**

I am aware that travelling expenses will be compensated at a rate of *R2.50 per km* (door-to-door). It remains my responsibility to keep an accurate travel log which will be used to calculate remuneration of travel costs.

This will be paid on completion of all the interviews via EFT / cheque / cash (please indicate preferred method of payment).

I agree that all information and data shared by the participants in the interviews will remain strictly confidential.

Signed: _____ Date: ____/____/____ (dd/mm/yyyy)

Thank you for your willingness to be a part of this project

APPENDIX FOUR:

PARTICIPANT INFORMATION FORM

Good day,

My name is Ruthann Sedgwick. I am a speech and language therapist currently involved in research towards a Master of Arts (Speech Pathology) degree at the University of the Witwatersrand. I would like to invite you to participate in my study.

I am conducting a research project entitled “*Parent Caregivers’ Experiences of Caring for Their Adult Child in the South African Context*”. The aim of this study is to investigate experiences of parents whose adult children have suffered strokes, aneurysms and brain injuries and, because of the results of the event, these adult children now require the care of their parent/s.

This information will help to develop support programmes for people with injuries and their parent caregivers. This study will also help to identify specific needs and difficulties associated with caring for an adult child.

If you agree to participate in this project, a trained counsellor will conduct an interview with you and you will be asked some questions about your experiences of caring for your adult child. You will also be asked to complete a short questionnaire giving details of your child’s injury and other relevant information

This should take approximately 60 minutes. In order to allow me to analyse the responses to the questions, the interviews will be audiotaped. You will be interviewed in your home or at a location convenient for you.

Your name and any other personal details will not be revealed to anyone else. Once the interviews are completed, the audio recordings will be stored on digital discs and later analysed by me. No copies of the recordings will be made available to anyone else nor

will they be played or broadcast by anyone other than me or my supervisors for the purposes of the research.

Participating in the research project will not have any direct benefit for you. There is also no risk to you. Counselling will be made available to you after the interview if you would like to access these services.

If you do not wish to participate in the study, this will not jeopardise your current or future speech therapy treatment or involvement in any support group in any way. If you decide to participate, you will be free to withdraw at any stage and any recordings made will be destroyed. You do not have to answer questions that make you feel uncomfortable.

Ethical clearance for this study has been granted by the University of the Witwatersrand Human Research Ethics Committee. Should you have any queries relating to ethical clearance for this project, please contact Professor Cleaton-Jones (Chairperson of the Human Research Ethics Committee - Medical) at peter.cleaton-jones@wits.ac.za or 011 717 2635.

Please contact me at rsedgwick@telkomsa.net or 083 289 2100 or my supervisors, Professor Claire Penn or Dr Jenny Watermeyer at 011 717 4567 if you need any more information.

Thanking you in anticipation.

Kind regards,

Ruthann Sedgwick

APPENDIX FIVE:

PARTICIPANT CONSENT FORM

In signing this consent form, I agree to participate in this study.

I understand that:

- I am free to withdraw my consent and discontinue my participation in this study at any time.
- My personal information and that of my child will be treated confidentially.
- My anonymity in this study will be respected.
- Refusal to participate in this study will not prejudice me or my child in any way.
- There is no risk to me in participating in this study.
- There will be no benefit, financial or otherwise, to me as a result of my participation in this study.
- The interviews will be audio-recorded for later analysis by the researcher.
- I will be referred for counselling should this be necessary.
- If I have any questions at any time, they will be answered to the best of the researcher's ability.

Signed: _____

(Parent / Caregiver 1)

(Parent / Caregiver 2)

Date: ____/____/____ (dd/mm/yyyy)

APPENDIX SIX:

PHYSICAL AND FUNCTIONAL ABILITIES

The following questions explore your child's functional or physical abilities since the injury / stroke / aneurysm. Please answer these questions by ticking the appropriate block.

Is your child able to:

- | | | |
|--|------------------------------|-----------------------------|
| 1. Walk without assistance | ☐ Yes | ☐ No |
| 2. Walk with assistance | ☐ Yes | ☐ No |
| 3. Bath and dress without assistance | ☐ Yes | ☐ No |
| 4. Bath and dress with assistance | ☐ Yes | ☐ No |
| 5. Feed him / herself | ☐ Yes | ☐ No |
| 6. Use and respond to verbal conversation | ☐ Yes | ☐ No |
| 7. Write (e.g. complete forms, greeting cards) | ☐ Yes | ☐ No |
| 8. Read (e.g. for pleasure) | ☐ Yes | ☐ No |
| 9. Respond to instructions | ☐ Yes | ☐ No |
| 10. Use the telephone appropriately | ☐ Yes | ☐ No |
| 11. Use a computer / tablet / iPad | ☐ Yes | ☐ No |
| 12. Make decisions regarding finances | ☐ Yes | ☐ No |
| 13. Drive a motor vehicle | ☐ Yes | ☐ No |
| 14. Be alone in the home for short periods | ☐ Yes | ☐ No |
| 15. Administer his / her own medication | ☐ Yes | ☐ No |
| 16. Participate in cooking activities | ☐ Yes | ☐ No |
| 17. Complete household chores independently | ☐ Yes | ☐ No |

18. Earn a weekly / monthly income ☐ Yes ☐ No
19. Maintain friendships outside the home ☐ Yes ☐ No
20. Keep to a daily routine without reminders ☐ Yes ☐ No

Thank you for taking the time to complete this questionnaire.

APPENDIX SEVEN:

INTERVIEW GUIDELINES

1. Have things changed since your child's accident/illness/stroke?
2. Do you and your child experience difficulties communicating at home?
3. Are things very different from what you thought or planned they would be at this stage of your life?
4. What have you found has helped?
5. What would you have liked to have known before your child came to live with you again?