PATIENT AND FAMILY EXPERIENCE OF A CEREBROVASCULAR ACCIDENT: A PHENOMENOLOGICAL INQUIRY

by

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CHAPTER 1

INTRODUCTION

A Cerebrovascular accident (CVA) or stroke is a vascular illness where blood supply to the brain is affected, resulting in possible permanent tissue damage (Robinson, 1998). This condition is prevalent worldwide and accounts for a significant number of fatalities that are related to neurological diseases (Robinson, 1998). Stroke has a number of possible causes and effects, which are mostly physical and cognitive in nature. One of the least researched effects of stroke, however, has to do with the impact of stroke on the family once the patient/survivor eventually goes home from hospital for long-term management of the condition (Sife, 1993). The experience of a cerebrovascular accident by the patient and family is the topic of this research, and systems theory was selected as a lens to view and contextualize the research data and results, while phenomenological research has been chosen as the tool for collecting and analyzing the data from this research.

Jones (1993) suggested that when an individual complains of personal distress or when others, whether family or professionals, regard that individual as distressed, the usual western psychological response is to deal with that person alone. The idea of a family as a system of human interaction is relatively new in the area of psychology. A system can be described as a group of elements in interaction with one another over time, such that their recursive patterns of interaction form a stable context for individual and mutual functioning (Jones, 1993). Systemic thinking is regarded as representative of a paradigm shift from the linear causal investigation of problems. This is because it conceptualizes causality in circular terms, where each element acts on and is acted upon by another. Systemic thinking is considered recursive, multidimensional, multicausal, and multifactorial. In systemic thinking, the whole system is considered greater than the sum of its parts (Braverman, 1993). This hypothesis

is considered as true to the degree that living systems are open, which allows for the interaction with elements outside the system to exert mutual influence.

This study therefore asserts that these assumptions about systemic functioning imply that any external elements, such as illness, will be influenced by and in turn influence the interactions within a system, in this case a family system. This study explores, from a systemic perspective, the experience of illness, in this case a cerebrovascular accident (CVA) or stroke by a family. This is a case study of one family and adopts an intimate and subjective view of the problem, exploring meanings family members attach to the experience of stroke using a specific paradigm *(systems theory)* and a specific tool of research *(phenomenological research)*. Von Eckartsberg (1986) has described phenomenological research as a research approach that is intended to study the meanings of human experience in situations, as they spontaneously form in the course of daily life. The emphasis in this type of research is on the study of lived experience, that is, how an individual for example, reads, enacts, and understands his/her life involvement in his/her everyday experiences (von Eckartsberg, 1986).

1.1. Aim of the Study

"…as we go up the scale of orders of learning, we come into regions of more and more abstract patterning, which are less and less subject to conscious inspection. The more abstract-the more general and formal the premises upon which we put our patterns together-the more deeply sunk these are in the neurological and psychological levels and the less accessible they are to conscious control…" (Watzlawick, Beavin & Jackson., 1967, p.37)

A phenomenon remains unexplained as long as the range of observation is not wide enough to include the context in which it occurs. Failure to realize the intricacies of the relationship between an event and the matrix in which it occurs, between an organism and its environment, either confronts the observer with something "mysterious" or induces him/her to attribute to his/her object of study

certain properties the object may not possess (Watzlawick et al., 1967). This study is intended to be exploratory in nature and to explore the experience of cerebrovascular accident (CVA) by the individual and the family from a systems perspective using phenomenological research.

According to statistics from the Department of Environmental Affairs and Tourism in South Africa, a cerebrovascular accident or stroke is amongst one of the main causes of death in South Africa in 1999, accounting for 7.5% of deaths (http://www.ngo.no/soesa/nsoer/issues/social/state4.htm). According to the National Center for Health Statistics (1996), stroke is the third leading cause of death in industrialized countries. Being accountable for approximately 10% of all deaths, stroke is also considered the leading cause of serious disability in the US (Glass, Dym, Greenberg, Rintell, Roesh, & Berkman 2000). Much of the emphasis of studies related to post-stroke progression has been focused on physical and cognitive-communicative impairments. Studies of other aspects, such as the psychosocial implications of stroke on the patient and the family and support structures and their coping strategies, are less common (King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002).

1.2. Why Research Cerebrovascular Accident or Stroke?

Stroke is arguably a strategic site to the study of psychosocial intervention for traumatic and chronic illnesses because of the comprehensive disruption it often causes to stroke survivors' functional capacities across a vast range of psychosocial domains, including communication (verbal and non-verbal), emotional regulation, cognition, memory, attention, and coping ability. It is also argued that stroke represents a profound identity assault that threatens the patient's sense of self (Glass et al., 2000).

Systems theory was chosen as a lens to look at the stroke phenomenon in an attempt to map the family's experience of the event (stroke). This study utilizes the family systems perspective that views stroke survivors and their

support structures as complex, integrated open systems with pre-existing patterns, norms, rules, communication styles and roles (Glass et al., 2000).

This research was initially motivated by an interest in how individuals and families adapt and integrate into their interactions and identity, elements that arise during and after what may be perceived as a 'crisis'. Having worked with neurology patients in a hospital setting, the author became sensitized to how families sometimes react to a member having experienced stroke and the challenges thereafter of adapting to the effects that come with rehabilitation and adjustment to the experience.

This study rests on the assumption that variables surrounding the experience of stroke do not have meaning independently. They are meaningful only in relation to one another. The relationship between variables constitutes the concept of function (Watzlawick, et al., 1967). This study is exploratory in nature and employs an intimate and personal method (case study) of data collection and analysis in order to evaluate the experience of stroke according to the perspectives of the survivor and the family. The study aims to explore this experience psychosocially and interactionally. It also aims to explore the meanings the family attaches to the experience and their attempts to adapt and redefine their relationships. The study will hopefully contribute to a better understanding of the changes in internal family dynamics that may occur due to such a serious, traumatic and chronic illness as stroke. This may possibly lead to future research into psychological interventions designed for families with specific and unique needs such as dealing with stroke.

According to Moss and Tsu (King et al., 2002), sudden serious illness often results in disequilibrium, which triggers adaptive processes which are initiated to restore equilibrium (adaptation). These include cognitive appraisal of the significance of the illness, identification of adaptive tasks and adopting of coping skills. Contextual factors such as background, patient-illness and socio-environmental variables shape these coping factors (King et al., 2002).

1.3. Why the Methodology?

Phenomenological research was chosen for this study because the author was interested in a more intimate and subjective view of the experience in question. Phenomenological thinking has been identified as one way to assist in bringing forth a better understanding of, and access to psychological phenomena as spontaneously lived. The emphasis of this type of research is on an attempt to get to the truth of a particular matter, to describe phenomena in the broadest sense as whatever appears, in the manner in which it appears, that is, as it manifests itself to the consciousness of the experiencer (Moran, 2000).

1.4. OUTLINE OF THE STUDY

The study is structured in such a way that Chapter 2 will address the phenomenology of a cerebrovascular accident, while Chapter 3 will give an overview of systems theory. The research design employed by the study is covered in Chapter 4. The results are presented in Chapter 5, and the discussion of the results and the conclusion follow in Chapter 6.

CHAPTER 2

CEREBROVASCULAR ACCIDENT

2.1. INTRODUCTION

2.1.1. What is a Cerebrovascular Accident (CVA)?

A Cerebrovascular Accident (CVA) has been defined by Robinson (1998), as the sudden loss of blood supply to a region of the brain leading to permanent tissue damage. When blood flow to the brain is impaired, oxygen and important nutrients cannot be delivered. A cerebrovascular accident has also been referred to as a stroke. According to the literature cited by Robinson (1998), the annual incidence of stroke in the United States of America is approximately 400,000 cases per year. Stroke is perceived as the most common serious neurological disorder in the world and accounts for half of all acute hospitalizations for neurological diseases (Robinson, 1998). There are, however, dramatic variations of the age-specific incidence of stroke over a life course of people across different countries (Robinson, 1998).

Stroke incidence worldwide according to comparative studies, is said to have found similar age-adjusted rates of the occurrence of the illness in a number of countries (Robinson, 1998). A study conducted by the World Health Organization examining stroke rates in European and Asian populations found that the differences related to gender or countries were small in comparison to age-related effects (Robinson, 1998).

2.1.2. Pathophysiology of Stroke

There appears to be no unified diagnosis of stroke, as there are a number of different causes, each with a different pathology, different treatments and

different frequencies, incidence and prevalence (Sife, 1993). A cerebral infarct or ischemic stroke, intercerebral hemorrhage and subarachnoid hemorrhage have all been cited as possible causes of a stroke (Sife, 1993). A cerebral infarct has been identified as the most common reason for a stroke, which is identified by death of brain tissue caused by decreased or absent blood supply to a part or all of the brain for a long enough period so that brain tissue dies (Sife, 1993). A cerebral hemorrhage, however, occurs when a blood vessel has broken inside the brain and causes bleeding into the brain, usually resulting in the formation of a large clot creating a hematoma within the brain. This can destroy and compress brain tissue and cause dysfunction (Sife, 1993). Bleeding over the surface of the brain, or subarachnoid hemorrhage, is described as usually resulting from a rupture of an aneurysm on the surface of the large veins at the base of the brain (Sife, 1993). The different possible causes of stroke will be described in detail in subsequent paragraphs.

2.2. Causes of a Stroke

The most common cause of stroke is a blockage of an artery in the brain by a clot (thrombosis). The part of the brain that is supplied with blood and oxygen by the clotted vessel is then deprived of blood and oxygen, and the cells belonging to that part of the brain die as a result. Typically, a clot forms in a small blood vessel within the brain that has been previously narrowed due to the long-term damaging effects of high blood pressure (hypertension) or diabetes. Sometimes due to hardening of the arteries (atherosclerosis), a blood clot can obstruct a larger vessel such as the carotid artery in the neck going to the brain (Medicinenet, 2004).

Another type of stroke occurs when a blood clot or a piece of atherosclerotic plaque (cholesterol and calcium deposits on the wall of the inside of the heart or artery) breaks loose, travels through open arteries, and then lodge in the brain. When this occurs, the flow of oxygen-rich blood to the brain is

blocked and a stroke occurs. This type of stroke is referred to as an embolic stroke (Medicinenet, 2004).

A cerebral hemorrhage, as discussed before, occurs when a blood vessel in the brain bursts and bleeds in to the surrounding brain tissue. Such a cerebral hemorrhage can cause a stroke by depriving blood and oxygen to parts of the brain. The accumulation of blood that results from this can also press on parts of the brain and cause damage. A subarachnoid hemorrhage, however, is caused by the rupture of a blood vessel that is usually located between the outside of the brain and the inside of the skull. The blood vessel located at this point of pressure is usually previously abnormal, resulting from what is called an aneurysm or an abnormal ballooning out of the wall of the vessel. Subarachnoid hemorrhages often cause a sudden, severe headache and are often complicated by further neurological problems such as paralysis, coma or even death (Sife, 1993).

Overall, the most common risk factor of stroke has been identified as high blood pressure and increasing age (Sife, 1993). Diabetes and certain heart conditions are the other most common factors. The occurrence of stroke in younger individuals (less than 50 years old) is usually associated with less common risk factors. These factors include drugs such as cocaine or amphetamines, ruptured aneurysms, and inherited, genetic predispositions to blood clotting. Another form of a cerebrovascular accident has been defined as a transient ischemic attack (Sife, 1993).

2.2.1. Transient Ischemic Attack (TIA)

A transient ischemic attack (TIA) is a short–lived episode (less than 24 hours) of impairment to the brain that is caused by a loss of blood supply. A TIA results in loss of function in the area of the body that is controlled by the portion of the brain affected. A clot that spontaneously forms in a blood vessel within the brain most often causes the loss of blood supply to the brain. This condition is also

known as a thrombosis. This can also result in a clot that forms elsewhere in the body, dislodging from that location, and traveling to lodge in an artery of the brain. This condition is known as emboli (Medicinenet, 2004).

Some TIAs develop slowly while others develop rapidly. Transient Ischemic Attacks by definition resolve within 24 hours, thus they are also known as "mini strokes" (Medicinenet, 2004). Strokes take longer periods to resolve than TIAs and reflect more permanent and serious problems. Although TIAs only last a few minutes and then end, most experts believe these should be evaluated with the same urgency as a stroke in an effort to prevent recurrences and/or a stroke. A Transient Ischemic Attack can occur once, multiple times, or precede a permanent stroke. These are often warnings of an impending, more severe or permanent stroke and must be immediately attended to by a physician (Medicinenet, 2004).

2.2.2 Treatment of a Stroke

Treatment of stroke involves mainly pharmacological intervention, rehabilitation and management of other medical problems contributing to the condition. One of the most important new treatments includes the use of anticoagulation drugs (drugs that thin the blood). It is, however, unclear if this treatment improves the outcome from the stroke currently experienced by a patient or simply helps prevent subsequent strokes. It has been shown that, given immediately after the stroke incident, this type of treatment improves the patient's outcome from the stroke over the long term (Medicinenet, 2004).

The rehabilitation aspect of treatment usually occurs when a patient is no longer acutely ill after a stroke and the health care staff focuses on maximizing the patient's functional abilities. This process is most often done in an inpatient rehabilitation hospital, in a special area of a general hospital or in a nursing facility (Medicinenet, 2004). The process of rehabilitation can include some or all of the following: (1) speech therapy to relearn talking and swallowing; (2)

occupational therapy to regain dexterity in the arms and hands; (3) physical therapy to improve strength and walking; and (4) family education to orient them for caring for their loved one at home and possible challenges they will face (Medicinenet, 2004).

The goal of rehabilitation is for patients to resume as many as, if not all, of their pre-stroke activities and functions. A patient's ability to return to his/her pre-stroke status is unfortunately not a goal of rehabilitation since a stroke involves the permanent loss of brain cells and a certain amount of permanent damage. When a patient is ready to go home, a nurse may periodically come to the home until the family is familiar with caring for the patient, and physical therapy may also continue at home. Patients are eventually left at home at the assistance of caregivers (Medicinenet, 2004).

The other aspect of treatment involves managing other medical problems that the patient may have, which may impact on the stroke or on the recovery. This includes management of blood pressure, monitoring patients with diabetes and administering oxygen to stroke patients who may require this. This process occurs on an ongoing basis, concurrent with other forms of treatment (Medicinenet, 2004). It is apparent then that the nature, pathophysiology, and cause of a stroke, clearly have a lasting impact on the stroke survivors and their families.

The recovery process of brain injuries, including stroke, usually involve a recovery of some functions that were affected by the stroke. These include speech and physical impairments and the recovery process occurs over a period of two years, after which, the rate of recovery plateaus, and no significant improvements occurs thereafter (Sife, 1993).

2.3. Effects of Stroke on Survivors

Stroke is responsible for a number of physical and cognitive impairments in stroke survivors (Visser-Keizer, Meyboom-deJong, Deelman, Berg & Gerritsen,

2002). In addition to causing physical and cognitive impairments, a cerebrovascular accident or stroke can be responsible for alterations in the way patients express, experience or comprehend emotions. An emotional state, such as depression, has been described as having many components, including overt behavioural expression, cognitive processes and physiological changes, all of which might be affected by stroke (Visser-Keizer et al., 2002). Research cited by Visser-Keizer et al. (2002) also showed that emotional and cognitive changes following stroke were experienced by 50% of stroke patients. These changes included mental slowness, memory disabilities, less initiative and hyper-emotionality.

There is also evidence from the same research relating to patient awareness of deficits. A number of studies have identified a link between the location of the brain injury and the impaired awareness of deficits. Right hemisphere strokes have been linked to impaired deficit awareness. Diminished awareness of deficits has also been identified as a secondary effect of impaired cognition such as memory and reasoning deficits (Visser-Keizer et al., 2002). These effects of stroke have been associated with depression, anxiety, and social isolation among stroke survivors (King et al., 2002). A discussion of the emotional disorders associated with stroke will follow next and this discussion identifies the strong link between these emotional disorders and the prognosis and progress of stroke patients.

2.3.1. Emotional Disorders Related to Stroke

Neurologists and Psychiatrists have identified language disturbances after stroke as frequently associated with emotional disorders (Robinson, 1998). This is mainly because language disturbances such as aphasia are common in stroke patients and are easily recognized behavioural manifestations of dominant hemisphere brain damage. Speech is also intimately associated with emotions and thoughts (Robinson, 1998). Language is divided into either intellectual

(conveying content) or emotional (expressing feelings) aspects. The language component of stroke indicates that emotional expression is distinct from spoken language and that stroke may produce disorders of emotion without producing disorders of language function. Emotion and behavior are perceived not only as introspective, but also as connected to anatomy and physiology (Robinson, 1998).

Robinson (1998) has identified certain themes where psychiatrists view stroke as producing clinical disorders which occur with stroke patients, such as depression, while neurologists tended to describe unique forms of emotional change that were only seen after brain injury, such as indifference reaction. The long-term nature of depression after a stroke involves what is described as "melancholic moods" lasting for months and sometimes longer, appearing frequently (Robinson, 1998).

Neurologists have also described disorders that are associated with specific lesion locations in stroke patients, such as frontal lobe or parietal lobe syndromes, or behavioural disorders, which are unique to brain injury (Robinson, 1998). Some patients with stroke have been described as not able to acknowledge the existence of an obvious motor deficit. These patients are said to have "anosognosia" or the absence of recognition. When these patients are confronted with their physical impairment, they simply deny that anything is wrong. These patients also frequently display indifference to their impairments or inappropriate affect. This is often associated with right hemisphere lesions (Robinson, 1998).

Another emotional disorder that is unique to brain injury patients is known as the catastrophic reaction. This is described as the abrupt onset of emotional symptoms of frustration, depression, and embarrassment (Robinson, 1998). Lasting for durations of between a few seconds to a few minutes, the catastrophic reaction is characterized by a display of emotion (shouting, swearing, pounding fists, throwing things) followed by a return to the previous calm emotional state. The catastrophic reaction is described as a sudden outburst of emotion provoked by a cognitive task, which is based on the inability

of the patient to cope when faced with a serious defect in physical and cognitive functions. The catastrophic reaction is compared to a survival state, where survival becomes paramount in a pathologically changed individual. This survival does not necessarily have to be normal and ordered or disordered and inconsistent. Survival is perceived as embedded in physical and mental shock experienced by an individual and the individual sees this as catastrophic (Robinson, 1998).

The indifference reaction is yet another emotional disorder unique to patients with brain injury. This disorder is associated with right hemisphere lesions and is described as indifference towards failures, lack of interest in family and friends, the making of foolish and inappropriate jokes, and minimization of physical disability. The indifferent reaction is also prevalent in stroke patients with severe perceptual deficits and impairment in orientation (Robinson, 1998).

The last condition that is unique to brain injury is pathological laughter or crying. This disorder is associated with bilateral and often multiple lesions affecting the corticobulbar pathways at any level above the pons. Patients with this condition experience uncontrollable episodes of crying or sometimes laughter, which usually last only a few seconds but may be totally disconnected from their mental state. Sudden noises or non-emotional conversation may trigger an episode of crying or laughter that may lead to embarrassment and social withdrawal (Robinson, 1998).

There is a theme in the clinical descriptions of patients with emotional disorders following strokes, which has been prevalent over time. It appears that there is a relationship of the emotional disorder to the patient's psychological attempt to cope with the physical or cognitive impairments (Robinson, 1998). Stroke appears to be particularly stressful to an individual and this is mainly because the organs governing the emotional response to injury have themselves been damaged by stroke (Robinson, 1998). The discouragement and frustration caused by the disability experienced by survivors after a stroke could impede recovery from the stroke. Depression for instance, which is associated with cerebrovascular disease, is reactive and understandable since this is a result of

the most cherished organ of humanity, the brain, being injured. Depression after brain injury is emphatically understood and explained as a natural emotional reaction to a decrease in self-esteem produced by the combination of a life-threatening injury, the associated physical and intellectual disability, and the resulting loss of independence (Robinson, 1998).

There is a line of theory that suggests that brain injury may provoke specific emotional disorders, which are mediated through pathophysiological response to brain injury (Robinson, 1998). Another line of thinking emphasizes that emotional disorders are an understandable psychological response to the loss of ego integrity produced by brain injury (Robinson, 1998). Clinicians have long known that emotional disorders accompany stroke and that clinical disorders produced by brain injury can be divided into two categories. One category includes disorders in which the brain injury is perceived as a cause of emotional disorders that are also seen in patients without brain injury. These disorders are sometimes called symptomatic or secondary disorders and examples of which include depression, mania, anxiety disorders, and personality disorders. The other category of emotional disorders that occur after brain injury includes those that are unique to brain injury, such as the catastrophic reaction, the indifference reaction, anosognosia or denial of illness and the pathological display of emotion (Robinson, 1998).

Whatever the case may be, and whatever argument for or against the nature of stroke and its effects, the resultant cognitive, physical and emotional effects of strokes have been linked to lower levels of quality of life. The effects of stroke have also been linked to decreased social and physical functioning for the stroke survivors and their families or caregivers (King et al., 2002).

2.4. Effects of Stroke on the Survivor's Family

Stroke is a significant health problem. Most stroke survivors require chronic care and this usually entails care in a family setting. Recent changes in health care concerning treatment of stroke means that patients pass to rehabilitation and

discharge in a shorter time period and before complete recovery. This results in patients and their families dealing with residual problems (Bishop & Evans, 1995). Bishop and Evans (1995) described families in general as being different and unique. The impact of stroke on the family will be determined by the unique variables such as nature of relationships in the family, coping mechanisms, age of the stroke patient and so forth (Bishop & Evans, 1995).

On top of the cognitive, physical and emotional difficulties experienced by the survivor, with which the family has to deal, depression in both patients and caregivers is also prevalent (Bishop & Evans, 1995). All the effects of stroke on both family and patient have been cited as having a significant effect on family dynamics and gender role-playing (male/female roles) within the family (Visser-Keizer et al., 2002). This being the case, it can be argued that the experience of stroke cannot be just an individual experience, (i.e., the experience of a stroke survivor alone); it is shared experience, a family and even community experience. It is therefore essential for this present study to assess and analyze how families and the stroke survivors themselves perceive the experience of coping and dealing with stroke.

2.4.1. Family Perspectives on Stroke

Clemson, Fitzgerald and Mullay-O'Brien (1999) indicated that family roles and responsibilities can be a major determinant of the kinds of activities people resume after stroke rehabilitation. The research cited by Clemson et al. (1999) has shown that in the health care system and within most health-care professionals, the "sick role" has been used to describe the behaviour of stroke patients. The sick role is perceived by Clemson et al. (1999) as based on western values and is characterized by what is described as a legitimate role for people with acute illness. The sick role is described as a passive role in rehabilitation and the patient in this role is not held responsible for the condition. The main duty of the patient in the sick role is to try to get well (Clemson et al., 1999).

There has been argument in current research cited by Clemson et al. (1999) for movement towards a description of rehabilitation that is at the level of meaning, in particular the meaning of the situation from the patient's perspective or meaning within the context of the familial role, responsibilities, and expectations. Familial relationships have been identified as having a greater impact on outcomes than the functional capacity of the patient. Research by Clemson et al. (1999), conducted over a two-year period found that understanding the experience of the family from a social and cultural perspective was crucial to understanding the adaptations that occurred following stroke. This research further indicated that people across different cultures have different and varying explanations of illness, even when working within the same medical models. The research also found varying responses to understanding brain injury and what happened when a family member experiences a brain injury, which is believed to be influenced by family roles and communication.

Outcome of research cited by Clemson et al. (1999), supports what they claim is growing evidence of the idea that if health care professionals are to address the rehabilitation needs of patients, and understand their behaviour in the rehabilitation context, health care professionals then need to understand the rehabilitation experience from the perspective of all key family members. One way that has been identified to understand these issues is to listen to people's "stories of rehabilitation", "clinical tales", and the use of narratives to understand human experience, including the experience of chronic illness (Clemson et al., 1999). Another aspect that is essential to the understanding and the contextualization of the experience of stroke by survivors and their families are their coping mechanisms.

2.4.2. Coping with Trauma or Crises

One way of comprehending the impact of traumatic events is through exploration of cognitive changes that confront the traumatized individual. The psychological

aftermath of trauma is perceived as multidimensional and thus can be approached from different perspectives (Magwaza, 1999). Research cited by Magwaza (1999) purports that there are three categories of basic assumptions by which an individual construes reality: benevolence of the world, meaningfulness of the world, and self worth. Benevolence of the world is defined as the extent to which people view the world positively or negatively, and to what extent they think good versus bad events occur. Meaningfulness of the world refers to people's beliefs about the distribution of good and bad outcomes. This involves making sense of the extent to which those outcomes occur and how they are distributed, that is, who receives what outcomes and why certain things happen to certain people. Self worth on the other hand have been defined as the assumptions that include the individual's belief that he/she himself/herself is good, worthy, and highly moral, engaging in behaviours considered proper and precautionary (Magwaza, 1999).

Magwaza (1999) argues that individuals' functioning is based on unquestioned and unchallenged assumptions and that traumatic events challenge people's assumptions and threaten their sense of coherence and stability. He further argues that traumatic events may shutter fundamental assumptions and beliefs about people and about the world. A study by Magwaza (1999) found that people who had been through a traumatic experience compared to those who had not, experienced people and the world as less benevolent and less meaningful. These research findings, however, indicated that people's self worth was not impaired and that this was mainly due to them considering the occurrence largely as a growth experience (Magwaza, 1999). Other research by Bolger, Forster, Vinokur and Ng (1996) suggested that when people adjust to life crises, close relationships appear to suffer over time. This apparently results from supporters in a close relationship with the person in crisis becoming overwhelmed by chronic exposure to the victim's difficulties and concomitant distress (Bolger et al., 1996). It is argued that support that is given in times of crisis may be effective in reducing crisis associated with difficulty and distress (Bolger et al., 1996). The supporters, however, may unintentionally

hinder functional recovery by enabling and encouraging the patient to remain physically inactive. Supporters unwittingly contribute to patients' distress when their support attempts are accompanied by expressions of hostility or criticism of the patient or hopelessness and despair about the patient's prognosis (Bolger et al., 1996).

2.5. CONCLUSION

According to the literature cited by King et al. (2002), Magwaza (1999) and Bolger et al. (1996) on stroke and on trauma or crisis, the unique situation in which families of stroke survivors and the stroke survivors find themselves in becomes apparent. There are possible difficulties in adjustment, adaptation, redefinition of roles in the family and attaching meaning to the experience and rearranging belief systems.

In order to understand the situation that families of stroke survivors find themselves in, it is important to understand the nature of families in general and how families function as a unit. Systems theory describes how systems and families function and will be used as the lens with which to view this study. The next chapter will explore systems theory and how it can be applied to stroke survivors and their families.

CHAPTER 3

SYSTEMS THEORY

3.1. INTRODUCTION

"Family systems is a way of thinking,
not a garage for repairing families"
(Selvini-Palazzoli, 1978, p.45).

3.1.1. What is a System?

Hall and Fagen defined a system as a set of objects, with relationships between the objects and between their attributes, in which the objects are the components or parts of the system, attributes are the properties of the objects, and relationships tie the system together (Watzlawick et al., 1967). They further argued that any object is ultimately specified by its attributes. The 'objects', may be individual humans, and the attributes by which they are identified are their communicative behaviors. In interactional systems, the objects are best described, not as individuals, but as what are termed as persons-communicating-with-other-persons (Watzlawick et al., 1967). Interactional systems consist of two or more communicants in the process of, or at the level of, defining the nature of their relationship. What is regarded as important in this process, is not the content, of communication per se, but rather the relationship aspects of human communication (Jones, 1993).

Another crucial aspect in defining a system is the definition of its environment. For a given system, the environment is defined as the set of all objects of which the change in attributes affects the system and also those objects whose attributes are changed by the behavior of the system. A system, together with its environment, is considered to make up the universe of all things

of interest in a given context (Jones, 1993).

With regard to the study of living (organic) systems, a system, according to systems theory is open to the extent that there is exchange of materials, energies, or information with its environment. A system, however, is considered closed if there is no import or export of energies in any of its forms such as information, heat, physical materials, etc., and therefore no change of components. It is noted, however, that human systems cannot be totally closed (Schultz, 1984).

3.1.2. General Systems Theory

General systems theory has its roots in the 1920s work of von Bertalanffy (Schultz, 1984) in the field of organism biology. The core notion is that an organism is an open system, that is, a system that maintains its integrity while interacting (exchanging information) with its environment. General systems theory considers the relationship of a whole object or entity as consisting of interacting parts and interaction with its environment (Schultz, 1984). Minuchin (1981) argued that the individual is part of a whole and not a whole in himself/herself. According to Western scientific thinking, traditional, non-systemic psychology looks at the individual as a whole consisting of parts and explains the behaviour of the whole (the person) in terms of its constituent parts (Schultz, 1984). Systemic thinking, however, perceives the individual as a part of a larger whole rather than as a whole in itself. The behaviour exhibited by a part (the person) is explained in terms of its relationship with other parts (such as the environment) and its function for the whole system. Systemic thinking implies a departure from Western scientific explanation of what constitutes a system and how an individual's role is defined and functions in it. Systemic explanation is what philosophers call functional or teleological explanation. An individual's behaviour is explained in terms of its function within the larger system (Jones, 1993).

3.1.3. The Characteristics of Open Systems

The family, as an open system, is considered to show certain system characteristics and these are as follows:

- *Wholeness,* which is the interrelation and interdependence in the behaviours of family members. This includes non-summativity which is considered as the property of being more than the sum of the parts;

- *Feedback,* which is considered as the assumption that the system will respond to input from its members or from the environment with the amplification or inhibition of pattern, in a way that ensures its own continuance;

- *Equifinality,* which implies that the same consequences or endpoints may be reached from different starting points or triggers. This is mainly because the organization or process of the system is more significant than its initial condition or any identifiable 'cause' (Jones, 1993).

3.2. Basic Concepts of Systems Theory

According to systems theory, linear causality does not exist. Emphasis is on reciprocity, recursion, and shared responsibility. In the context of relationships, *a* and *b* influence each other and both are equally cause and effect of each other's behavior. Patterns characteristic of the relationship between *a* and *b* then establish over time (Becvar & Becvar, 2000).

In systems theory, the main concern is not why something is happening in a particular relationship, but what is going on in the relationship in order to describe patterns in the relationship. A systems perspective is holistic and focuses on the processes, or context, that give meaning to events instead of only focusing on the individuals or events in isolation. The focus is present-centered and is concerned with examining here-and-now interactions rather than with looking at the history of the event in question (Becvar & Becvar, 2000).

One of the characteristics of systems theory is a worldview of theoretical relativity. This approach attempts to transcend the either/or dichotomies by acknowledging the necessacity for, or complementary nature of, both sides of the "coin", if the "coin" exists at all (Becvar & Becvar, 2000). The concept of theoretical relativity acknowledges that it is impossible to reject one side of the coin or issue, without destroying the coin entirely. Embracing one theory does not necessarily require or imply the rejection of a different theory. Systems theory is aware that different theories give meaning to each other and each theory's usefulness is context specific. Systems thinking, therefore, does not negate the theories about individual psychology (Jones, 1993).

Systems theory, however, is also described as a theory that is not pragmatic. It is mainly a "skeleton of science" and gives a framework on how to speak about the problem or view the problem if the observer wants to understand events or change them (Becvar & Becvar, 2000). Systems theory, according to Becvar and Becvar (2000), does not offer a method of how to make necessary changes in the system. Systems theory was later adopted by family therapists for its ability to describe human living. However, they also drew from a variety of other sources, such as individual psychology, anthropology, biology, cybernetics, and communications theories to build their theories (Becvar & Becvar, 2000).

3.3. The Family as a System

A family is considered as a system since it fits the definition of a system. A family, as a system, is described as stable, depending on certain of its variables, and if these variables remain within defined limits (Watzlawick et al., 1967). The behaviour of every individual within the family is perceived as related and dependent upon the behaviour of all others in the family. All behaviour is considered as communication and it therefore influences and is influenced by others. Change for the better or worse in a family member, who is the 'identified patient' (i.e. the person identified as playing the sick role) of the system, will

usually have an effect on other family members (Watzlawick et al., 1967). The family is usually affected in terms of their own psychological, social, or even physical health (Jones, 1993). Inputs (equifinality), which are actions of family members or of the environment, if introduced into the family system, are acted upon and modified by the system (Jones, 1993). According to the systems perspective, a family is perceived as a group of individuals interacting within the context of the family (O'Connor & Lubin, 1984). Some families can absorb large setbacks and even turn them into rallying points, while others appear unable to handle the most insignificant crises. Some families, however, completely negate the input and feedback in the system. These families simply do not acknowledge or act on the input or feedback in their system (Jones, 1993).

In this proposed study, all these systems principles and thinking will be taken into consideration and used as a lens to look at the 'data' collected. Some of the basic postulates of systems theory have identified something that is considered generally true of families. The family exists in the context of human problems (such as conflict, trauma, crisis etc.) and like other groups, families have emergent properties that make them different from individual persons in the group. The other postulate is that the process and not the content, reveals what is most significant about family interactions (Capps, 2000). There are theories in systems thinking which give explanation on how systems, including families, function and are organized. The theory of cybernetics, although expanded on over time, is one of them.

3.4. Theory of Cybernetics

3.4.1. Cybernetics Defined

Cybernetics is defined as the study of systems that can be mapped using information loops within networks that define the flow of information (Bateson, 1972). The idea of cybernetics was derived from a Greek word that means "pilot"

and translates to "the study of feedback" (Littlejohn, 2001). Cybernetics is a theory of systems based on communication (transfer of information) between systems and the environment. This theory also deals with systems and feedback structures within these systems, and how the systems in turn relate with the environment (Bateson, 1972). Cybernetics focuses on how systems function and the manner in which they control their actions, and how they communicate with other systems, or with their own components. At its inception, cybernetics was interested in the similarities between autonomous, living systems and machines. During this era, there was a fascination with the new control and computer technologies which tended to focus attention on the engineering approach (Littlejohn, 2001).

Bateson (1972) argued that there is a difference between causal explanation and cybernetic explanation. Causal explanation is usually positive in nature and describes a positive relationship. According to this approach, billiard ball *b*, for example, moves in a certain direction because billiard ball *a* hit it at a certain angle. Cybernetic explanation, however, is negative in nature and considers alternate possibilities that could have conceivably occurred and then asks why many of the alternatives were not made. According to cybernetic language, the course of events is said to be subject to restraints within such an event, and assumes that apart from such constraints, the pathways of change would have been governed only by equal probability (Bateson, 1972). As movement toward a better understanding of how this theory relates to human systems apply, other theories were formulated.

3.4.2. First-Order Cybernetics

In first order cybernetics, the scientist or "engineer", will study a system as if it were a passive, objective entity, which can be freely observed, manipulated and taken apart. The concepts essential to first-order cybernetics includes concepts

of information, circularity, feedback, punctuation, redundancy, and mapping and territory (Jones, 1993).

According to Bateson (1972), human systems are more adequately described in terms of information/communication, rather than in terms of energy. The ideas of feedback and recursiveness or circularity have been crucial in enabling system therapists to conceive of human interactions in ways that move beyond simple determinism, *a* leads to *b* and leads to *c*. Human systems are regarded as showing circular interaction, i.e. action *a* leads to action *b*, which might lead action *c*, which might in turn give rise to action *a*. Individuals are therefore seen as responding to feedback and eliciting it in relation to those significant others with whom they interact. The interaction is said to be recursive in nature (Bateson, 1972).

Feedback is characterized as positive (eliciting more of the antecedent behaviour) or negative (eliciting less of such behaviour). This idea of feedback in circular interaction then offers an explanation of how systems remain stable or change (Bateson, 1972). First-order cybernetics is characterized by an assumption that the observer stands outside the thing observed, and he/she is therefore objective. The observer is then able to intervene from the position of a detached observer, who remains unaffected by interaction, and is someone who is in a position to make objective observations and judgments about the system (Jones, 1993). In human systems, judgments made would involve judgments of pathology, dysfunction, normative goals, and how to intervene in the system in order for change to be observed in the system. A family is then seen as a self-regulating system, which controls itself according to rules formulated over time through a process of trial and error (Jones, 1993).

3.4.3. Second-Order Cybernetics

There has been some confusion about the difference between cybernetics and general systems theory. Some theorists have used the two terms

interchangeably, while others have argued that the two are different languages that apply to distinct but overlapping domains (Schultz, 1984).

Becvar and Becvar (2000) do not distinguish between cybernetics and systems theory. They use these terms synonymously and interchangeably. They, however, distinguish between what they term *simple cybernetics* and *cybernetics of cybernetics*. According to the theory of simple cybernetics, an observer places himself/herself outside the system and observes what goes on in the observed system (first-order cybernetics) (Becvar & Becvar, 2000). The observer, in simple cybernetics, does not see himself/herself as either part of the system, and is not concerned with why it does what it does. The focus is on describing what is happening. The different characteristics of a system are scrutinized from an outsider's perspective (Becvar & Becvar, 2000).

The theory of cybernetics of cybernetics, however, takes an upward movement on the level of abstraction. According to this theory, one is no longer merely an observer of the system. At this level of abstraction, systems are no longer viewed only in the context of inputs or outputs, or their relatedness to other systems (Becvar & Becvar, 2000). The observer becomes part of, or a participant, in that which is being observed. Everything that takes place is entirely self-referential. Whatever is observed also reflects the properties of the observer (Becvar & Becvar, 2000). This approach is known as second-order cybernetics (Jones, 1993).

Second-order cybernetics or cybernetics of cybernetics is concerned with recursive connections between systems, and the complexity of layers of cybernetic processes. According to this perspective, the observer is seen as part of the system that is being observed, and is also crucial in constructing that which is being observed (Jones, 1993).

At the level of cybernetics of cybernetics, boundaries of the system remains unbroken, and the system is viewed as closed (Becvar & Becvar, 2000). There is a shift of focus from a behavioural analysis, based on inputs and outputs with an emphasis on the environment, to a recursive analysis that emphasizes

the internal structures of the system and the mutual connectedness of the observer and the observed (Becvar & Becvar, 2000).

The theories on how systems function, or are regulated, give a broad idea of how systems in general are structured (Bateson, 1972; Becvar & Becvar, 2000; Jones, 1993; Schultz, 1984 & Watzlawick et al., 1967;). It is, however, necessary to explore how these theories apply to families in specific situations. The following paragraphs will explore the theories of how systems theory relates to families in crisis.

3.5. The Systems Model of Stress: ABC-X Model of Family Crisis

The ABC-X model of stress has been considered as the dominant family stress theory for almost half a century (Clark, 1999). The ABC-X model purports that a stressor *(A)* interacts with the family resources in order to deal with crisis *(B)* and with the definition the family makes of the event *(C)* to produce the crisis *(X).* A stressor is regarded as a life event that may produce change in the family's social system. Another proposal in the ABC-X model has been what is defined as the taxonomy of family stressors. Some of these are relevant to illness: the origin of the stressor (within or outside the family); the impact (on all or some family members); the onset (sudden or gradual); the severity (intense or mild); the required period of adjustment (short or long term); and the predictability (expected or not) (Clark, 1999).

Some of the limitations that have been identified in the ABC-X model are the positivistic assumptions that underlie the model and some inconsistencies in the assumptions that are applied in the model. The model was perceived as fundamentally positivistic in nature because its purpose was to identify relationships that specify deterministic patterns (Burr & Klein, 1994). The ABC-X model was viewed as positivistic in nature because it was based on the assumption that variables that operate in family stress operate in a relatively mechanistic, linear, and cause-and-effect matter. In the last two decades some

scholars have tried to break away from some of the limitations of the ABC-X model by making it more systemic and finding ways to make it more consistent with non-positivistic ways of thinking (Clark, 1999).

According to the newer version of the ABC-X model, it is postulated that when a family is not experiencing stress, there is a fairly predictable repetition or redundancy in the patterns of daily routines and events. The family members are perceived as interacting with little difficulty, and the family systems are involved in processes of transforming inputs and outputs. Families transform inputs such as energy, time, and space into outputs such as meaning, affection, and power. Other inputs are described as including behaviours, money, and information while other outputs include love, attention, discipline, growth, development, satisfaction, bonds, heritage, closeness, learning and security (Burr & Klein, 1994).

Developmental changes and unexpected changes constantly create some change (morphogenesis) in family systems, but during relatively calm periods the morphogenetic tendencies are moderated by morphostatic tendencies. This results in a system that has manageable levels of change and order, innovation and constancy, and creativity and predictability. As a result of the continual balancing and rebalancing of the needs the people have for togetherness and separateness, the system is always responding to generational, emotional, affective, economical, social, and ecological factors both outside and inside the family. During times of stress, however, it is theorized that the family undergoes developmental transitions and stages (Burr & Klein, 1994).

According to the new ABC-X model, the first stage in this model is known as the *pre-trauma phase,* where the family is functioning at a normal state, before it experiences a particular stressful situation. The second stage is called the *acute coping phase* and this is characterized by a stressful event being an input that precipitates a transition into the second stage. This stage is described as a period of disorganization. As time passes, families eventually experience another transition. When the disorganization reaches the lowest levels, the family is said to move into the third developmental stage or *the recovery stage.* During the

recovery stage families tend to use a variety of coping strategies to try and manage the disruption introduced by the stressful situation. The *angle of recovery* follows the *recovery stage,* which is defined as the time it takes a family to reach stability in relation to the adjustment to the change they are experiencing (Burr & Klein, 1994). During this stage, if the family's coping strategies do not readily adjust to the stressful event, the angle of recovery becomes larger, and the family may continue in a disrupted condition for a long period of time. The final stage occurs at the end of the recovery period and it occurs when deliberate coping ends and the families are past the recovery process. This is a period of a *new normal level* of functioning for the system (Burr & Klein, 1994).

The ABC-X model purports that although the stages defined in the model are linear, that is, one seems to succeed the other in a linear manner, the process of crisis that a family experiences is very circular in nature. The inputs and outputs in the family system and how these interact with the environment are informed by and in turn inform each other (Burr & Klein, 1994). The crisis a family experiences is a system on its own, within a larger family system, and crisis is a process that informs the larger system and is in turn informed by the same system (Clark, 1999). The family appears to be in a constant struggle between change and stability, which is captured by the final stage of the crisis model, which is described as an attempt to find a *new normal level*, or in other words, an attempt to find stability (Burr & Klein, 1994).

It is, however, important to evaluate the possible shortcomings of the systems perspective and way of thinking. Although systems theory and thinking has been around for some time and it has had a lot of comprehensive appraisal, it is also important to explore possible shortcomings of the theory.

3.6. Criticism of Systems Theory

One of the criticisms of systems theory is what Braverman (1993, p.286) describes as family therapists having *"thrown the baby out with the bath water".*

She warns against losing the individual in the possibly excessively global thinking linked with systems thinking. She argues that in an attempt to move away from individualistic and psychodynamic thinking, family therapists may have done this at the expense of the individual in the system. Braverman (1993) acknowledged the usefulness of systems thinking in that it assists in understanding the reciprocity of relationships in the present, she however argued that this type of thinking neglected the individual's developmental history. Systems thinking places emphasis on interactions, communication, and patterns or relationships in a system and, according to O'Connor and Lubin (1984), concentrating mainly on family trends, may lead to the neglect of individual personality systems and/or the environmental context of the family's activities.

According to Capps (2000) the individual family members have their own selfhood. This implies that each member has his/her own personal story, much of which intersects with the stories of the other family members but much of which has its own reality, independent of the family. Individual family members are perceived as having different interests and these different interests have their effects on family dynamics. Family members are considered much more than just their stories and the process involved in their family interactions (Capps, 2000). The way family members interact, gives more information about how they function as a family than does what they actually talk about. Attending to the process of family conversations is seen as having a clarifying effect, where instead of getting lost in the details, the observer steps back and sees how the family interacts (Capps, 2000). Exclusive focus on process is also seen as denying the validity of the competing interests in the family and the real basis of interactions in the family. Complete focus on process is argued to be reductionistic and neglects the content of personal experiences of each family member, which are treated as if they are not very important (Capps, 2000).

3.7. CONCLUSION

A system is argued to be influential, but not deterministic (Braverman, 1993; Capps, 2000). The idea of a system as having enormous power to determine the lives of those who participate in it, may lead to a sense of fatalism and may produce a fatalistic view of family members' ability to initiate change. This is seen as deflating the individual's own powers of self-determination (Capps, 2000). There is therefore, an argument for a more holistic view of the family as a system that appreciates different levels of variables involved in their interaction, such as individual personality systems, the environment within which the interaction occurs and the impact of these on each other.

When a system is viewed from the cybernetics of cybernetics perspective (second-order cybernetics), for example, the observer, in the case of this study, the researcher, will inevitably have an impact on the research participants and the research data itself in this study (Becvar & Becvar, 2000). According to Becvar and Becvar (2000), whatever the observer sees, reflects the observer's properties. It is thus important to identify a research method that addresses this issue.

Taking the view of the individual's self-determination powers also into account, it is important for this study to get a more subjective view of the problem straight from the individuals involved. The phenomenological research method was selected as the tool to be employed in this study to make sense of and contextualize the data in this study. The nature of phenomenological research, when applied correctly, is said to allow for "bracketing" of preconceived notions about the research problem and allow for the "voice" of the participants to be heard (von Eckartberg, 1996). The next chapter will discuss the origins and nature of this research method in more detail.

CHAPTER 4

RESEARCH DESIGN

4.1. INTRODUCTION

> *"In the garden of a country house, in plain view of passers-by on the sidewalk outside, a bearded man can be observed dragging himself, crouching, round the meadow, in figures of eight, glancing constantly over his shoulder and quacking without interruption. This is how the etiologist Konrad Lorenz describes his necessary behaviour during one of his imprinting experiments with ducklings, after he had substituted himself for their mother. "I was congratulating myself" he writes, "on the obedience and exactitude with which my ducklings came waddling after me, when I suddenly looked up and saw the garden fence framed by a row of dead-white faces: a group of tourists was standing at the fence and staring horrified in my direction." The ducklings were hidden in the tall grass, and all the tourists saw was totally unexplainable, indeed insane behaviour".*
>
> *(Watzlawick et al., 1967, p.20)*

The above quotation illustrates the importance of understanding and attaching meaning to behaviour within a context. It is postulated that systemic thinking has helped therapists have a greater appreciation of context and has helped to break the monopoly of psychodynamic thinking (Jones, 1993). This is one of the reasons a systemic paradigm was chosen as a lens for this study. A phenomenological research method was, however, selected as a tool of collecting and analyzing the data from the case study.

4.2. Psychology and the Science of Research

Some criticism of psychology has been that, although on face value it appears to be flourishing, a closer look at the psychological literature quickly indicates discrepancies between the psychological phenomena studied and the methods by which they are studied (Smith, Harré, & Langenhove, 1995). The main

complaint is with regard to the largely unquestioned ontological and epistemological basis of psychology. According to Smith et. al., (1995), psychology has two major features: One is regarded as relating to its form: the way psychology is actually institutionally organized within the totality of the social sciences. The other is related to its method: the way psychologists proceed methodologically (Smith et. al., 1995).

Psychological thinking and even psychological research covers an incredible number of activities, many of which fall under different headings, depending on the selected point of view (Thinès,1977). With psychology being a field of knowledge with such a great diversity of 'points of view', Thinès (1977) suggested that it would be difficult then to consider psychology as truly scientific. Furthermore, psychology is normally regarded as an autonomous institutionalized scientific discipline. It is the assertion of Smith et. al. (1995), then, that neither psychology nor any other social science can be regarded as "natural" sciences. This argument postulates that on the contrary to the two (psychology and the social sciences) being considered as natural sciences, they both constitute human practices and should thus be regarded as the historical origins of certain social sciences.

Earlier arguments by Thinès (1977) also purport that psychological thinking is usually influenced by different schools of thought, and depending on the person's school of thought, clinical psychologists, for example, tend to think that psychological work can and even should be done without any mathematical treatment. Experimental psychologists, however, seem to feel uneasy if their results were expressed in everyday language, so they tend to use mathematical formalism in the way they conduct their research and how they expound results from that research.

There is currently a line of thinking (Giorgi, 1985; Smith et al., 1995) that holds the view that psychology has had a longer past and a shorter history than the natural sciences. The implication of this statement is that there was a progression in the development and liberation of psychology from its pre-scientific past, just as chemistry and physics were once "liberated". This also

implies that there has been a natural progression in the development of the history of psychology (Smith et. al., 1995). The very first prerequisite for the emergence of a science is that certain phenomena are considered possible objects of study. This according to Smith et. al. (1995) implies that at any given time, one has to be allowed to study something, one has to have the desire to study something, and that one has to have the ability to study something. The assertion is that any phenomenon can only be subjected to a scientific study if these three conditions are fulfilled. The pre-scientific past of research in the social sciences has been perceived as having been restricted by the socio-economic formation of the time, religious obstacles, and politics of the time (Smith et. al., 1995). With the emergence of new practices, specific actions in which people and/or society were the object of study was required, and pre-existing ideas and knowledge were critically questioned. It is argued that at the dawn of the emergence of social sciences as institutionalized practices themselves, two modes of studying people and society were available. One model was the model of the natural sciences and the other was the model of hermeneutics (Smith et. al., 1995).

Hermeneutics is defined as the work of interpretation, the art of the technique of reading. According to this model, text and documents do not offer direct access to what they mean but they have to be interpreted in order to discover what the text or author of the text meant. It is maintained that hermeneutics as a model for the social sciences basically means that one considers persons and societies as if they were texts where discovery of meanings occurs (Smith et. al., 1995).

The research model of the natural sciences implied that only observable phenomena could be studied (Giorgi, 1985). This model was aimed mainly at the search for causality and favours quantitative forms of analysis and is related to a positivistic philosophy of science.

Giorgi (1985) furthermore asserts that sensation, perception and consciousness, which are not observable phenomena, are hard to analyze despite their prevalent appearance and mention in psychological literature. He

also argues that for a long time in the nineteenth-century, there have been controversies about the nature of psychological subjects, which were perceived as mechanical models designed to fit the positivistic nature of the natural sciences. The hermeneutic mode, however, is aimed at the search for meaning, favours qualitative analysis that generates knowledge of particulars, and is related to non-positivistic philosophies of science (Smith et. al., 1995).

4.3. Natural Sciences vs. Human Sciences

There has been argument by Giorgi (1985) against the use of the natural scientific framework to study human phenomena. According to this argument, there is a discrepancy between the natural scientific framework adopted by psychology and the essential characteristics of human phenomena as they spontaneously unfold in everyday life. Psychology is seen as being in a dilemma of either meeting the scientific criteria established by the natural sciences, or else identify itself with another scholarly framework such as arts and humanities, and thus admitting to not being a science (Smith et al., 1995). Giorgi (1985) has identified phenomenological thinking as one way of escaping this dilemma. Phenomenology is perceived as not only a purely philosophical dispute that tends to deprive scientific psychology of its theoretical as well as its practical achievements (Thinès, 1977). This line of thinking raised the question of whether psychology could be legitimately considered a fundamental science (Thinès, 1977). Phenomenological thinking can also assist in bringing forth a better understanding of, and access to psychological phenomena as spontaneously lived. This type of thinking is also perceived as being able to assist one to harmonize psychological phenomena with an expanded idea of science (Smith et al., 1995).

Giorgi (1985) also suggested that the fundamental fact missing in the natural scientific approach but present in phenomenological thinking, is that objects usually studied in natural sciences lack consciousness, while those

studied in human sciences have consciousness. According to this argument, concepts, methods, and criteria of the natural sciences were introduced and developed in dialogue with phenomena that lacked consciousness such as stones, stars, molecules, neutrons and so forth. When human sciences adopted the natural sciences framework, researchers imitated the framework without a critical evaluation of the effect that a conscious human subject as the 'object of study' might have on the framework that was being employed.

Science deals with knowledge. Phenomenologists, however, emphasize the idea that knowledge is always related to consciousness (that is, someone must be aware of it), and that knowledge is constantly of or about some thing or event (Smith et al., 1995). This implies that on the one hand, there is constantly a human subject, who underlies the act of knowing, but on the other hand, the object of knowledge can be a thing or event that is lacking in consciousness, or it can be another human with full consciousness (Smith et al., 1995). Giorgi (1985) therefore, suggests that although there are still many unresolved problems surrounding the use of descriptions in psychological research, the overall assumption is that a qualitative analysis of descriptions can yield psychological insight of a value that at the least has the same value as quantitative approaches, although different in character and style. One of these methods is obviously phenomenological research.

4.4. Theoretical Background of Phenomenology

4.4.1. What is a Phenomenon?

It is suggested by Smith et al. (1995) that a thing exists in space and time, and is subject to the regularity of causal laws such as, if *A* then *B*. By maintaining the same conditions and repeating the same antecedent, one can observe the same results in the treatment of things. In addition, if the variables such as space and temporal relations are kept the same and respected, one can perform many

proper determinations. It is argued, however, that while a thing itself can be subject to causal and linear analysis, the perception of the thing, or the perceived thing is not subject to such analyses. The act of perceiving is considered to belong to consciousness and the thing perceived is considered as neither the act of perceiving nor the thing itself. The terminology to account for the thing as perceived is called a *phenomenon* (Smith et al., 1995). Some other ways to illustrate the difference between the thing itself and the thing as perceived are for example the act of speaking and what is spoken, the act of dreaming and what is dreamt, and so forth. The point being made is that the method of analyzing the thing as perceived needs to differ from that used to analyze the thing itself (Smith et al., 1995).

According to Moustakas (1994) the word *phenomenon* means to bring to light, to place in brightness, to show itself in itself, and the totality of what lies before us in the light of day. The word, according to him, is derived from the Greek word *phaenesthai,* meaning to flare up, to show itself, to appear. A phenomenon is thus what appears to the consciousness (Moustakas, 1994). Phenomenology, therefore, refers to knowledge as it appears to consciousness or the science of describing what one perceives, senses, and knows in one's immediate awareness and experience (Moustakas, 1994). This process then leads to an unfolding of phenomenal consciousness through science and philosophy, which is described as a process towards absolute knowledge of the "absolute" (Moustakas, 1994).

4.4.2. What is Phenomenological Research?

Phenomenology has been described as a philosophy that thematizes consciousness and all the objects, events, processes, etc., which we become aware of by means of consciousness. It is also considered a method for accessing all the objects and events that our consciousness refers us to (Valle, 1998). Phenomenology is arguably better understood as a radical, anti-traditional

style of philosophizing, with emphasis on the attempt to get to the truth of matter, and to describe phenomena in the broadest sense (Moran, 2000). This description of phenomena describes a phenomenon as it appears, in the manner in which it appears, that is, as it manifests itself to consciousness of the person experiencing something (Moran, 2000). Phenomenological research rejects quantitative methods of science and insists that these methods are inadequate to treat the nature of consciousness for principally two reasons: (1) consciousness itself is perceived as not an object like most objects in nature, and (2) there are conscious phenomena which cannot be dealt with in science. Phenomenology does not limit its investigation to just those realities which are objective in a materialistic or naturalistic sense. Phenomenology is considered to offer a considerable broadening of the range of philosophical inquiry just as much as phenomenologists make no assumptions about what is or is not real, they rather begin with the content of consciousness (irrespective of what that content may be) as valid data (Stewart & Mickunas, 1990).

Phenomenological research describes phenomena experienced individually or by many individuals at one time or another. It explores everyday experiences which do not have the clarity, precision or systematization that one expects of a scientific perspective (Giorgi, 1985).

Edmund Husserl is considered the originator of philosophical phenomenology (Giorgi, 1985; von Eckartsberg, 1996). He articulated what is considered central insight, which purports that consciousness is intentional, i.e., he argued that human consciousness is always and essentially orientated towards a world emergent with meaning (von Eckartsberg, 1996). Husserl was mainly concerned with the discovery of meaning and essences in knowledge. His belief was that a sharp contrast exits between facts and essences and between the real and non-real (Moustakas, 1994). According to Husserl, consciousness is always "of something". His argument purports that experiences are constituted by consciousness and therefore could rigorously and systematically be studied on the basis of their appearance to consciousness (von Eckartsberg, 1996). This suggests that experiences are studied on the basis of their phenomenological

nature, and this occurs when an appropriate method of reflection or phenomenology is used (von Eckartsberg, 1996). According to Husserl's theory, besides the explication of experiences, this method enables one to reflect upon and articulate the most essential structures of consciousness (phenomena) which he argues are intentionality, temporality, spatiality, corporeality, perception, cognition, intersubjectivity and so forth. It is thus suggested that as philosophy, phenomenology has become the reflective study and explication of the operative and thematic structures of consciousness, i.e., it is primarily a philosophical method of explicating the meaning of the phenomena of consciousness (von Eckartsberg, 1996).

According to Husserl's methodology, the beginning of such study involved what he called phenomenological reduction or "epoche", which involved the attempt to put all of one's assumptions about the matter being studied into abeyance, or to "bracket" them. Giorgi (1985) argues that if this step is omitted in the reflection on personal experiences, it leaves one open to the "psychologist fallacy". This means that there is likelihood that one's judgment about such experiences will be biased by various preconceptions, wishes, desires, motives, values, and so forth (von Eckartsberg, 1996). According to this perception, only when the bracketing or suspension of such preconceptions has been achieved can the natural attitude be said to give way to a more disciplined "phenomenological attitude" from which one could grasp essential structures as they themselves appear. Bracketing as a process has been described as the following:

> "Bracketing means that one puts out of mind all that one knows about a phenomenon or event in order to describe precisely how to experience it…Husserl introduced the idea of the phenomenological reduction, which after bracketing of knowledge about things means that one is present to all that one experiences in terms of the meanings that they hold out for consciousness rather than simple existents" (von Eckartsberg, 1996, p.4).

The assumption of the phenomenological attitude implies that we describe something not in terms of what we already know or presume to know about it, but rather we describe that which presents itself to our awareness exactly as it presents itself. This movement is crisply formulated in the phenomenological imperative known as "back to the things themselves". The "things" referred to are defined as meanings as given perceptually through a multiplicity of perspectival views and contexts (Stewart & Mickanus, 1990).

Another assumption of the phenomenological approach is the rejection of presuppositions of what is "real". Although it has been argued that absolute freedom from presuppositions is impossible and that the view of a philosophy without presupposition is impossible, this is in itself a form of presupposition (Stewart & Mickanus, 1990). Husserl and subsequent phenomenologists argued for the suspension of all judgments about matters under study until they can be founded on a more natural basis. This is said to be achievable through "bracketing" or phenomenological "epoche". According to Husserl, after having reached epoche, philosophy begins its description and clarification of consciousness, unburdened by the assumptions of natural attitudes (Stewart & Mickanus, 1990). Phenomenological research is, however, characterized by many themes and concepts.

4.4.3. Themes of Phenomenology

Phenomenology is a reasoned inquiry, which discovers the inherent essence of appearances. The essence of appearance is anything one is conscious of. Anything that appears to consciousness is perceived as a legitimate area of philosophical investigation (Stewart & Mickunas, 1990). One of the general themes of phenomenology is that of consciousness. Consciousness is considered as intentional, which is another way of saying that consciousness is always directed toward an object (Stewart & Mickunas, 1990). It is frequently stated that consciousness is consciousness of something. Intentionality, is

perceived as being at the core of Husserl's theory (Moustakas, 1994). Intentionality, contrary to it being viewed as a causal relationship to the external, concrete, characteristics of things, Husserl viewed as an activity of consciousness which is identical with the object meant to be conscious of (Stewart & Mickunas, 1990). Intentionality shows the orientation of the mind to its objects, and how these objects exist in the mind in an intentional way (Moustakas, 1994). An intentional act, with reference to perceiving, is therefore, the act of perceiving something and judging of certain matter or valuing of the thing perceived. Intentionality refers to consciousness, which is described as the internal experience of being conscious of something. The act of consciousness and the object of consciousness, are thus said to be intentionally related (Moustakas, 1994).

This distinction of the intentional nature of consciousness arguably destroys any possibility of viewing consciousness as empty or closed in upon itself (Moustakas, 1994). Some of the implications of this way of thinking are that the emphasis is shifted from the question of the reality of the world to the meaning of that which appears to consciousness. All questions about the reality of the world are suspended, momentarily put out of question. There appears to be an intimate link between consciousness and the content of consciousness and this connection is fully manifested through phenomenological thinking. Consciousness is perceived as never empty and abstract but is linked to the world of experience. In phenomenology there is a shift of attention from the question of the reality of the world to its meaning as phenomena (Stewart & Mickunas, 1990). Based on the literature on phenomenological research, there appears to be a lot of wealth and meaning in the stories of clients in a therapy setting or subjects in a research setting.

Intentionality is made up of a noema and the *noesis* (Moustakas, 1994). The noema is described as the phenomenon, not the object; just the appearance of a tree is not the tree itself, for example. This means that the object that appears in perception varies in terms of when it is perceived, depending on the angle, the background used to perceive the experience, and the orientation of

wishing, willing or judging from the vantage point of the person perceiving the object (Moustakas, 1994). The noesis on the other hand, is described as the phenomenon as it appears without meanings and judgement attached to it (Moustakas, 1994).

Epoche is yet another theme and concept of phenomenology, and as described before, it involves "bracketing" of preconceptions regarding the phenomenon being perceived (von Eckartsberg, 1996). This term means to refrain from judgement, abstain from or stay away from everyday, ordinary ways of perceiving things (Moustakas, 1994).

Phenomenology as a form of research, appears to place great emphasis in the importance and usefulness of description in understanding certain everyday phenomena.

4.5. Power of Stories

Stories are said to have power and uses that are strong and varied. Some of the highlighted uses are the following three: stories can be used metaphorically, therapeutically and as historical legacy to provide a confirmed existence (Williams, 1995). Theorists such as Capps (2000) hold the view that there is a paradigm shift away from systems theory to stories in family therapy. The argument is that this movement has been fostered by the realization by some therapists that a story is the content of the therapeutic process and that the stories clients tell, should be what they are attentive to because within stories lie the very possibility for change. Stories by their very nature, are perceived as envisioning positive change (Capps, 2000).

Hearing of relationships, whether socially or therapeutically is considered possibly one of the easiest ways to glean stories (Capps, 2000). The mere mention of a person is seen as opening the door for questions and listening as the teller relates situations, conditions, emotions and an entire story waiting to be told. People are surrounded by others, where there is always a story, or two or

three or more, in each of them (Williams, 1995). All clients in the therapeutic setting are considered to have a story, and therapists are perceived as constructing parts of the story to understand the context of the client and his or her disability. Qualitative research is seen as providing an opportunity and the privilege of listening to people's stories (Clemson et al., 1999).

It is the assertion of White (1997) that expressions of lived-experience are shaped by meanings ascribed to the experience of grand narrative, and by the practices of life and relationship that are associated with these meanings. He perceives that these expressions in turn contribute to lived-experience, and thus, these expressions of life constitute what life is. These methods of description are, however, not without their limitations.

4.6. Limitations of Phenomenological Research

Some of the main difficulties surrounding phenomenological research include the biographical presence of the researcher, relativity of interpretation, and difference between interpretation and truth (Valle, 1998). The researcher's background concerning the topic, his/her previous disposition to the research topic, cultural background, gender, political affiliation and so forth will influence how the data is interpreted (Valle, 1998). This links to the question of relativity of interpretation, where the argument is that the interpretations of findings are not simply "given" but are "captured" or taken out of a constantly elusive matrix of happenings. This therefore implies that possible meanings in "data" are revealed as a function of the researcher's questions and perspectives on the data. Research results are thus perceived as no more and no less than possibilities of interpretation of the data (Valle, 1998). In similar vein Fourie (1996) expressed the opinion that research results are "constructed", not "discovered".

When the question of verification in interpretive research is asked, what is actually asked is a question about the experience of truth (Valle, 1998). Furthermore, to understand the meaning of the experience of truth

phenomenologically, the meanings expressed in the culminating description of a piece of interpretive research can be perceived to exist in a movement of constant relativity of validity, which always depends on the meaning, context, and interpretive framework of the individual looking at the data (Valle, 1998). This line of thinking suggests that whether one is judging the coherence of a single narrative description or the congruency of two or more narrative descriptions, the question of coherence remains a matter of personal judgment. Reliability is thus said to become a second-order question of agreement or "fit" among observations that are presumed to have achieved a "fit" at the more primary level with regard to validity (Merriam, 2002).

Internal validity, which is the extent to which one's findings are congruent with reality, and reliability, which refers to the extent to which research findings can be replicated, have been pointed out as areas of criticism against qualitative research (Merriam, 2002). Since no one narrative description can in practice embrace the "whole" phenomenon, the adequacy of a particular description is judged in view of its limited grasp of the phenomenon, and so an equivalence of described observations is either merely coincidental or is established by the perceived "hanging together" of different descriptions from different viewpoints (Valle, 1998). According to Giorgi (1985), the assumption underlying phenomenological research is that even if there are some problems with descriptions, these can be corrected with other descriptions. This in other words means that, just as poor or false perceptions can be corrected with better or true perceptions, so too can inadequate descriptions be replaced by more adequate ones (Giorgi, 1985).

The distinction between validity and reliability is said to become blurred in qualitative research, to the extent that in the process of determining whether or not one set of findings is congruent with another, one must make one's own assessment of how well, if at all, the findings have illuminated their target. In the end, it is suggested that the value of the findings depends on their ability to help others gain insight into the ever-mysterious realities of human life (Valle, 1998).

4.7. Design of the Study

According to Smith (2003), there is an intimate reciprocity between the method of data collection and the data itself. Smith (2003) argues that if one wants behaviour observation to be the basis of data, then one must situate the method accordingly and if one wants to use statistical procedures, one should alternatively respect the assumptions of the procedure chosen and be sure that the appropriate numbers are obtained. What is key in phenomenology, is how a person/s actually lived through and interpreted a situation/s, and how the database often comes from retrospective descriptions (Smith, 2003).

Three basic steps of empirical phenomenological study have been outlined by von Eckartsberg (1986) and these were employed in this study. These are as follows:

- **Step 1:** *The Problem and Question Formulation - The Phenomenon.* In this step the researcher delineates a focus of investigation. The researcher formulates a question in such a way that it is understandable to others.
- **Step 2:** *The Data Generation Situation - The Protocol Life Text.* This step involves the researcher starting with a descriptive narrative provided by subjects who are viewed as co-researchers. During this stage, one queries the person and engages in dialogue with the subjects or combines the two.
- **Step 3:** *The Data Analysis - Explication and Interpretation.* At this step, once the data is collected, it is read and scrutinized so as to reveal its structure, meaning configuration, coherence, and the circumstances of the data's occurrence and clustering. The emphasis at this point is on the study of configuration of meaning involving both structure of meaning and how it is created.

The first step suggested by von Eckartsberg (1986) was completed during the initial stages of this study where a proposal for the study was compiled with a

detailed formulation of the research problem. The second step involved deciding on a research method, and a data collection and analysis method. As already mentioned, the phenomenological research method was selected for this study. The data collection and analysis method of the study will be explored next.

Moustakas (1994) expanded further on the steps of empirical phenomenological research by differentiating between the Van Kaam method of data analysis and the Stevick-Colaizzi-Keen method of data analysis. The method that is employed in this study is the Van Kaam method of data analysis. Each of the steps in the method of data analysis is presented in an appropriate order of analysis and is as follows:

Using the complete transcription of each research participant:

1. *Listing and Preliminary Grouping*

   List every expression relevant to the experience. (Horizonalization)

2. *Reduction and Elimination:* To determine the Invariant Constituents:

   Test each expression for two requirements:

   a. Does it contain a moment of experience that is necessary and sufficient constituent for understanding it?

   b. Is it possible to abstract and label it? If so, it is a horizon of experience. Expressions not meeting the above requirements are eliminated. Overlapping, repetitive, and vague expression are also eliminated or presented in more exact descriptive term. The horizons that remain are the invariant constituents of the experience.

3. *Clustering and Thematizing the Invariant Constituents:*

   Cluster the invariant constituents of the experience that are related into a thematic label. The clusters and labeled constituents are the core themes of the experience.

4. *Final Identification of the Invariant Constituents and Themes by Application: Validation.*

   Check the invariant constituents and their accompanying theme against the complete record of the research participant: (1) Are they expressed implicitly

in the complete transcription? (2) Are they compatible if not explicitly expressed? (3) If they are not explicit or compatible, they are not relevant to the co-researcher's *(participant's)* experience and should be deleted.

5. Using the relevant validated invariant constituents and themes, construct for the co-researcher *(participant)* an *Individual Textural Description* of the experience. Include verbatim examples from the transcribed interview.

6. Construct for each co-researcher an *Individual Structural Description* of the experience based on the Individual Textural Description and Imaginative Variation.

7. Construct *for each participant* a *Textural-Structural Description* of the meanings and essences of the experience, incorporating the invariant constituents and themes. (Moustakas, 1994, pp. 120-121).

These steps and structures of analysis were used in this study to gather and generate "results" and themes from the study.

4.8. CONCLUSION

It seems that concepts are not things or substances or forces at all, they are rather meanings or structures forged by the mind in its experience of things (Edie, 1987). The world is neither true nor false, nor is it meaningful or valuable in itself. It takes on meaning only in relation to a mind, which orders or relates the parts, which therefore institutes objects of thought, and by thinking of the world, introduces the relationship of knowledge, and of possible truth or falsity (Edie, 1987).

Phenomenology is precisely the discipline that tries to discover and account for the presence of meanings in the stream of consciousness (Giorgi, 1985). It is the type of discipline that tries to sort out and systematize meanings and if a way could be found to do qualitative research, this could possibly be done through exploring the phenomenological approach.

The next chapter will present the "results" section of this study and information about the participants involved in this study. The next chapter will then be followed by a discussion section where the results will be discussed in terms of the literature explored in this study.

CHAPTER 5

RESEARCH RESULTS

5.1. Background Information on the Participants

The family who participated in this study consisted of seven members. Only four of the members could be interviewed. The family is of African decent and consisted of a mother, a father and four children plus one grandchild. The husband was the stroke survivor in the family. The family consisted of three daughters aged 21, 19, and 17 respectively, while the youngest child was a son aged five. The grandchild was aged two and is the son of the eldest daughter. The daughter aged 19 does not live with the family because she stays with her grandparents. The four members who were interviewed were the husband, the wife and the two daughters. This is mainly because other children in the house were too young to be interviewed and the one daughter did not reside with the family.

The father in this family (the survivor) is employed as a civil servant in a senior managerial position, while the wife has been a housewife since the husband suffered a stroke. The husband is 55 years old and the wife is aged 42. The two daughters are still studying. The husband suffered from a stroke in October 2002 while on duty. He has a history of hypertension and was on medication for this condition before the stroke.

Due to the stroke, the husband currently has a speech impairment and other physical impairments affecting the right side of his body. He cannot use his right arm at all (has slight sensation) and walks with a limp in his right leg.

5.2. Selecting the Sample

Due to this being a case study and exploratory in nature, the sample family was chosen on a voluntary basis. The researcher approached a number of support groups and organizations that deal with stroke survivors and their families and requested the assistance of families interested in the study. The research problem was explained to all potential participants and the family who then ended up participating in this study volunteered to be part of the study. The family was not in any way coerced or remunerated for being part of the study. All the interviews took place at the participants' residence.

5.3. Ethical Considerations

All participants were briefed on the nature of the study and they were all required to sign consent forms to be able to participate in the study. Participants signed two separate consent forms, one on consent to be part of the study and the other on consent for the use of audio material to collect the data *(see Appendix B)*. Confidentiality was guaranteed (no use of identifying information) and the family participating in the study was debriefed after the interviews and will be furnished with the findings of the analysis of the data.

5.4. Data Collection

The data in this study was collected through the use of semi-structured interviews, using an audiotape recorder to record the interviews. The structure suggested by Smith (2003) on how to conduct semi-structured interviews in phenomenological research was employed in this study. He suggested that the investigator must have a set of questions on an interview schedule, but that the interview has to be guided by the schedule and not be dictated by it. Smith

(2003) lists the following as the goals and criteria of this type of interview structure:

- An attempt should be made to establish rapport.
- The ordering of the questions is less important.
- The interviewer should be free to probe interesting areas that arise.
- The interviewer can also follow the respondent's interests and concerns.

Smith (2003) also suggested that, while constructing the questions for the interview/s, two things should be noted: Firstly, one should ask questions that are neutral rather than value-laden or leading. Secondly, one should avoid jargon or assumptions of technical proficiency. During the interview itself, Smith (2003) also advises the following:

- *The interviewer must try not to rush.* He/she must give the respondent time to finish a question before moving on, since often the most interesting questions need some time to respond to, and richer, fuller answers may be missed if the interviewer jumps too quickly.

- *The interviewer must use minimal probes.* If respondents are entering an interesting area, minimal probes are often all that is required to help to continue, for example, *'Can you tell me more about that? or 'How did you feel about that?'*

- *The interviewer should ask one question at a time.* Multiple questions tend to be difficult for the respondent to unpack and even more difficult for the researcher subsequently when going through the transcript.

- *The interviewer should monitor the effect of the interview on the respondent.* It is sometimes possible that the respondents feel uncomfortable with a particular line of questioning, and this may be

> expressed non-verbally. The researcher should be able to rephrase the
> question or contain the situation.

The researcher in this study followed the above guidelines when collecting the data. The husband and wife were interviewed together, while the two daughters were also interviewed together, but separate from the parents. The researcher was concerned about the possibility of either group not responding candidly to the questions because of the presence of the other. There was only one set of interviews with both groups and the interviews were conducted in Zulu, and were later translated to English during transcription. After the interviews and collection of the data, the analysis process began using the Van Kaam analysis method (Moustakas, 1994), which was described in the previous chapter.

5.5. Results of the study

Using the Van Kaam method of analysis of phenomenological data *(see Chapter 4 for detailed description)*, the following was established:

5.5.1. Horizonalization: *(This is the first step in the analysis of the data)*

The horizonalization process described in the Van Kaam method of analysis entails listing of every expression relevant to the family's experience of stroke. This step is followed by the identification of invariant constituents and themes. Excerpts that are representations of the essence of the family's experience were selected and these excerpts were perceived to entail all the expressions from the interviews that are relevant to the family's experience of stroke. Horizonalization requires the selection of parts of the verbatim transcription of the interviews that entail the core of the experience researched, and the elimination of all the parts that do not add to the expression of the experience. Once this part of the analysis

process was completed, themes were extracted from the excerpts selected in the horizonalization process. The step of identifying invariant constituents and themes will be discussed next and will be accompanied by examples from excerpts selected during the horizonalization process *(see Appendix A for the full transcription of the research interviews).*

5.5.2. Final identification of the Invariant Constituents and Themes

This process constituted the application of Steps 2 and 3 of the Van Kaam method of analysis. The following is the thematic portrayal of the family's experience of stroke:

1. *Family role redefinition and redefinition of social identity* - The data revealed that a major part of the experience of stroke involved the redefinition of roles within the family and society. The following is an example of an excerpt identified through the horizonalization process:

I= interviewer ; W= wife ; H= husband; D= 1st daughter and S= 2nd daughter

I: Can I then ask you as the wife *(of survivor), what does it mean to you for your husband to have suffered a stroke?*

W: To me, it means that our lives are not that different. I mean, he needs more care than before. He also can't do the things he used to do before. His temper is also different.

I: The temper is different in what way?

W: The thing is, since he had the stroke, he is short-tempered. The things he used to do for himself, he can't anymore.

I: Things like what?

W: Things like housework work normally done by the man in the house, you know. He can't do these things anymore and it means I have to do most of that

work now.

I: So far, for you *(husband)*, what does it mean to have suffered a stroke?

H: What it means is that my wife has to be responsible for most things and be a wife and husband in the family. I cannot do most things so she has to also play the role of the man of the house. There is no place for feeling sorry for yourself.

I: How is it for you now that the roles in the family have changed?

H: You know what? This thing *(stroke)*, I have told myself that what has happened has happened and unless I have a chance to improve, this is my situation. If I improve, it's fine. I just need to worry about my life now, so I can be free, and take care of my life and the children.

> This process of role redefinition involves loyalty to the greater "good" of the family and also empathizing with the patient/survivor. The process is, however, extremely frustrating for all involved and requires a lot of support structures, mainly within the family itself. An example of this is as follows:

I: How are your friends and family reacting to all this considering you don't get a chance to see them?

W: I actually don't consider that anymore…I'm actually not worried about their reaction. My main concern is my family and what is happening here.

The next except was taken from the interview with the two daughters and pertains to the theme of redefinition of social roles:

I: Something I didn't ask you, how is this affecting your social lives…like boyfriends?

S: Well, that, we have excluded from our lives.

2. *The adjustment process* - This process is also very dominant in the family's experience of stroke and this involves dynamics such as the fight for conservation of the family versus the imminent change being faced, and also the need for acceptance of the current situation versus hope for improvement of the situation. The following are examples of the process the wife and the daughters are experiencing with regard to adjustment:

I: For you then, as the woman of the house, how do you specifically deal with the situation?

W: Well, you get used to it. At the beginning, you of course have a lot of stress, but with advice it gets better. After a while, you get used to the situation and it becomes as though it's natural…It just becomes like part of your job as a wife.

I: Can I ask you then, what about you as a person, what qualities, enable you to have such patience and acceptance as opposed to other people who may not?

W: People are not the same... So, if you do not have the qualities, you need to learn patience and all those qualities you don't have... If you know your partner is sick and you say you love them, then you just have to learn to be patient. Even if he makes you angry, just remember that it is due to the illness. You should remember that before, he was not like this...If you know that you don't want to assist the person when he needs your help, this also emotionally hurts him. He also starts losing hope and starts feeling like now that he is sick, he is useless. I see that my husband appreciates my efforts. He has said from his mouth that he appreciates the support I have given him through his illness. Even his friends comment on the difference a supportive partner makes. So I try, although sometimes I'm under a lot of pressure, I try not to show it… then the other person starts worrying and feeling like they are a burden.

The next except describes one of the daughters' experience of the adjustment process:

I: So, what was it like for you at the beginning when your father first came out of hospital?

D: Well, sometimes we didn't understand. When he had temper tantrums and outbursts, we did not always understand.

Individual personality traits and dynamics also seem to come into play and each individual applies these in order to adjust. There is, however, a constant challenge on these individual traits and dynamics. The following is, for example, is 'S''s account of her struggle with the adjustment process:

I: And what about you *"S"*, what has the process been like for you?
S: Eeish! It took me longer to adjust. It took me about 2 months. Firstly, we had to adjust to the language problem, and then something comes up, like the short temper and then there is something else.
I: So, is it a constant adjustment?
S: Yes.

3. *Loss of independence* - This theme is consistent for all the family members, although varying in degree and intensity. The patient/survivor's loss of independence is clearly obvious, while the rest of the family has had to sacrifice some independence in order to contribute towards looking after the patient/survivor. The wife, for example, has identified this theme as one of the most difficult aspect to deal with in relation to stroke:

I: Now then, tell me what is the most difficult thing for you at the moment?
W: …I can say his loss of independence. When things are really bad, then I have to help him bathe, go to the toilet and get dressed, you see. This is very difficult…The second difficult thing is that I cannot go and visit family and friends. You always have to be around in case he needs something, you know. I also worry about him when I'm away that he may be lonely on his own.

4. *The challenge of belief systems* - This theme is mainly prominent with the husband and wife, where there are dynamics around hopes and fears, and rationalization versus reality. The following is an account of how the wife perceives their situation:

I: Some people believe certain things happen for certain reasons and some believe things happen at random. What is your belief?

W: Actually, we are still unsure. Some people will tell you this and some will tell you that. So, we don't really know why it happened.

I: So tell me, for now, with you being a mother and a wife in the family, what is your biggest fear?

W: Well, I don't have a lot of fears now. I mean, the stroke did not kill him…We believe that if God decides to take him, at least he will die with a light heart…If God decides to let him live, it is also fine.

5. *Frustration* - This process involves frustration within other areas or themes of the experience, for example, the family role redefinition and social identity redefinition. There is, however, overall a general theme of frustration. There is frustration with the patient's impairments, social ignorance, rejection from society and frustration with lack of information about the illness and the treatment process. The following excerpt was identified through the horizonalization process:

I: So according to you *(husband)*, as a stroke survivor, what is the most frustrating thing?

H: You know, usually people see you like this *(points at himself)* and they pity you. This makes me feel small.

W:…Ja, you feel like your condition is worse than you thought. When people pity you, you feel you are worse off than you are.

I: Is it difficult to accept pity from people or co-workers?

H: No, not really. I think I have moved past that.

I: … how has his language difficulties affected you?

W: Eish! That really affected us, you know. Sometimes he tries to say something and he can't say it properly. Then I just speak to him, or sometimes you can see what he is trying to say and you take the lead and ask him "do you want to say this and this?"

I: If someone were to ask you what it is like to try and say something and not be able to, what would you say that is like?

H: Ja, well…it's frustrating, it's really frustrating…You know, if you want to say something and something else comes to the tip of your tongue, it's frustrating. When there is more than five things, then it's really difficult.

The two daughters articulated their frustration about the experience of stroke as follows:

I: What is the most difficult thing to get used to?

S: The short temper and his language problem. Sometimes he gets so frustrated when he wants to say something that it looks like he is going to cry.

D:…We also need to think on our toes in order to find out what he wants to say

I: Do you think people understand what stroke is?

D: Ag! Some people don't understand. They think the person is crazy. When they talk to him, they talk as if they are talking to a small child.

I: How do you feel about that?

D: Sometimes, I feel like stopping them because I know he *(father)* does not like it. Sometimes people come and tell him how bad his condition is, while he feels he is actually improving. He sometimes thinks he is improving and they tell him otherwise.

6. *Uncertainty -* Although the general message from the family was that of hope, hope that the patient will recover fully or more than at present, there was an implicit and underlying message of uncertainty about the recovery process and the future in general. The overwhelming message was,

however, that of hope for the future. The wife and the two daughters *(from their separate interviews)* expressed their feelings about the future as follows:

I: Are you anxious or not about possible relapse or change in your *(husband)* condition?

W: No,…no, we are not. As far as we are concerned, he is getting better. I worry that maybe he will fall sick or something, but otherwise, we are fine.

(The next except is from the interview with the two daughters):

I: So, from your side *"D"*, you said at the beginning of the interview that you think this condition does not look like it will change. What do you think will happen if it doesn't change?

D: Well, it's really something we are getting used to. All we are waiting for now is for him to get better.

S: I feel things will go back to how they were before.

I: So you are hopeful?

S: Yes.

I: And if the condition does not change?

D: Then we need to get used to the condition.

After the step of identifying the invariant constituents and themes was completed, the text from the horizonalization process was used to identify individual textural descriptions.

5.5.3. Individual Textural Descriptions

This part of the analysis process was somewhat of a challenge since the participants were interviewed in pairs, which was imperative in order to get a more coherent and less fractured exploration of the family experience. The

following is the textural description of each individual derived from the paired interviews:

5.5.3.1. Textural description of the wife's experience of Stroke

The experience of stroke for the wife was mainly that of new roles and identity within the family. The wife wanted to conserve what the family used to represent but was faced with the reality of the current situation. To her the stroke "means that our lives are not that different…he needs more care than before. He also can't do the things he used to do before…". The wife was also faced with adjustment which challenged her character and emotions and she indicated that she had to "…learn to control your own temper…it becomes as though it's natural…It just becomes like part of your job as a wife". The process also involved a feeling of loss of independence on the part of the wife, where she had to give up her job and made sacrifices relating to her friends and family. She, however, learnt to prioritize her family's needs. "…My main concern is my family and what is happening here".

The wife's belief systems were also challenged where she had to face her fears and also to acknowledge her helplessness in influencing the situation. The wife had hope for more recovery in the future, but was willing to accept it if the situation did not change. "…We now believe if God decides to take him, at least he will die with a light heart…If God also decides to let him live, it is also fine".

The wife also felt empowered throughout the whole process. She feels that the experience had brought her and her husband closer. "We are very close". She also felt affirmed throughout the process. "…I see my husband appreciates my efforts. He has said from his mouth that he appreciates the support I have given through his illness…".

The wife experienced frustration throughout the process "…sometimes I'm under a lot of pressure…", but she remained loyal and empathetic to her husband "…I try not to show the pressure cause when you do show it, then the

person starts to worrying and feeling like they are a burden".

The wife also felt empowered concerning her ability to assist other families in a similar situation. She felt she could help them a lot, "…especially the wife…well, the man also".

5.5.3.2. *Textural description of the husband's experience of Stroke*

The husband also felt empowered by the experience. He feels it has brought his relationship with his wife closer. " We now know each other very well." He was also optimistic about the process. He felt that he and his wife "…are motivated…we want to raise our children so they have a better future" .

The husband has also adopted a stoic approach to his condition where he has acknowledged that this was his plight and he cannot shift responsibility to anyone else. He feels that "…what happens, happens!" and that the whole family, including him, had to accept this. The husband also acknowledged the role redefinition in family due to his condition but felt that "…there is no place for feeling sorry for yourself". He wants to put what had happened in the past and continue with his current life and plans for the future. He feels he just needed to worry about his life's condition presently so he can get his freedom from the illness and "…take care of my life and my children".

The husband's main frustration seems to be centered on information concerning the illness and his treatment. He feels that "…as far as I'm concerned, if I improve, I will be able to tell you that this and this and this happened…once I complete the process, I will be able to say more". His language impairment also seems to be his main frustration and he describes it as "really frustrating" and "really difficult".

The husband, however, has reserved judgment about the whole process until he can be able to say more about this. "Once I complete the process, I can be able to say something about that…".

5.5.3.3. *Textural description of "D's" experience of Stroke*

D struggles with the reality of what her father's condition means and hopes for progress. " …it's a painful condition without any hope of full recovery…but I hope he will get better and better." D also initially struggled with adjustment to her father's condition, and with the new definition of roles in the family. She feels the adjustment has been very difficult to achieve and she feels that it is mainly because of the family's patience that they are coping. "We have patience".

D has also identified through the process some of the qualities she feels are necessary to adjust. " I would say they need to have extra care and attention, and that they need to get used to the situation". D also acknowledges some of the challenges the family is faced with, which puts pressure on them to improvise. "…We also need to think on our toes in order to find out what to say".

D, like her parents, experiences frustration with society and ignorance concerning the illness. " Ag! Some people don't understand. They think the person is crazy. When they talk to him, they talk as if they are talking to a small child". She also acknowledges the positive effect the illness has had on her parents' relationship. "They are close now. They spend most of their time together…".

D struggles with acceptance of the condition and hope for improvement. She, however, feels that if the condition does not change, then the family needs to get used to this. She also feels empowered by the process. She has learnt " to be patient and to think on our feet". D has also experience some loss of independence and has had to make sacrifices in order to assist the family. She has had to suspend part of her social life, including having boyfriends and going to parties. "…Sometimes it's been very hard because friends invite us to parties and we sometimes can't go".

D feels the process the family is going through is a new experience and provides a learning opportunity for all of them. "…it is something new and we are learning to adjust." She, however, embraces the process. "…We understand and we are coping and adjusting".

5.5.3.4.   Textural description of "S's" experience of Stroke

S feels hopeful about her father's condition. She feels that there has been a general improvement in his condition so far. "…Initially, he couldn't walk or even use his hands…he will get better". She also experiences feelings of loss concerning how the family relates, and this is due to her father's illness. "…We also can't go to town as a family anymore…we do miss that".

S acknowledges the difficulty adjusting to the new set of circumstances, especially the impairments caused by the illness. "…Sometimes he gets so frustrated when he wants to say something that it looks like he is going to cry". She longs for the way things were before and feels hope of things going back to the way they were before. " I feel things will go back to how they were before".

S also admits that the process has been possibly harder for her and that she has required a longer period of time to adjust. "…it took me longer to adjust…" She also feels the loss of independence and the sacrifices made concerning her social life, including having relationship socially with guys. " Well, that, we have excluded from our lives".

5.5.4. Textural-Structural Description of the Family's Experience of Stroke

Since this research was a case study, and the intention was to explore the experience of stroke by this family, the researcher decided that the step of identifying the individual structural description should incorporate the family's structural description as a unit in order to get a holistic understanding of the structure of the experience from a family perspective, using the individual textural descriptions. The following is the family structural description of the experience based on the individual textural descriptions:

The structures that permeate the whole family's experience of stroke are overlapping and interlinked. Individual and personal traits and qualities differentiate the approaches of individuals in the family with regard to how they

cope with their current situation. The experience of stroke involves major role redefinitions in the family and everyone feels the need to accept and adjust. "…You get used to it...it just becomes part of your job …". The process also involves a lot of sacrifice on the part of each individual family member in order to sustain the new family roles and dynamics. " I don't even work …". The experience also brings partners close together, due to the process of being in constant company of each other and helping each other through the experience. " We know each other very well…we are very close…".

The experience of stroke by a family also involves a struggle between conservation of the past " I feel things will go back to how they were before", and the reality of the present situation and the future. The experience also includes varying degrees of loss of independence affecting all members of the family. " I don't even work now…". The loss of independence of the patient in the family is very obvious since it involves physical and other impairments that are perceivable. The other family members however, experience subtle losses, such as the children's loss of social relationships outside the house. " Well, that, we have excluded from our lives".

Frustration is also a major part of the experience of stroke by the family. The frustration affects the family at a micro level, e.g., the impairments of the patient, to the macro level of how society views the illness and relates to the family because of it. " …Some people don't understand. They think the person is crazy…". At the macro level, availability of information and proper medical treatment also influences the process of the experience of the illness at family level.

The experience of stroke by a family also involves a lot of uncertainty about the process and the future. The family's belief systems, including their hopes and fears are exposed due to this experience. There is a constant struggle between rationalization and reality. "…It's a painful condition without any hope of full recovery…but I hope he will get better…". The whole family's experience of stroke is, however, a process involving constant change and adjustment.

5.6. CONCLUSION

This chapter was a step by step description of how the data was analyzed using phenomenological research methods and how the data is arranged in terms of the research question. The following chapter will cover the results of this study in relation to the literature. This will be done in order to formulate a way of structuring the results in relation to current literature.

CHAPTER 6

RESULTS AND CONCLUSION

The results of the study resonate with the literature on what is described by Bishop and Evans (1995) as being a significant health problem, stroke. It is also clear from the results that the impact of stroke on the family in this study was modified by unique variables such as relationships in the family, coping mechanisms, and so forth. Although the family was faced with the redefinition of roles in the family and the struggle to adjust to their situation, variables such as personality traits, belief systems and family relationships came into play.

The results of the study also supported the assertion by Clemson et al. (1999) that familial relationships have a greater impact on outcomes than the functional capacity of the patient. The patient's attitude, self-esteem and self-perception, however, also appear to play an important role in the patient's functional capacity. In this study, the patient appeared to have a stoic attitude and a hopeful and positive outlook for the future, which in turn appears to impact on his motivation for the recovery process.

Family roles and responsibility also appear to be major determinants of the kind of activities stroke survivors resume after stroke rehabilitation, as suggested by Clemson et al. (1999). The family in this study experienced redefinition of roles and responsibilities in the family due to the patient having suffered a stroke. The stroke survivor in this study also appeared to suffer from what is described by Robinson (1998) as emotional disorders related to stroke. The stroke survivor experienced language disturbances, which resulted in a lot of frustration for both the patient and the family. Stroke appeared to be stressful and frustrating for the patient and the family, but contrary to the argument by Robinson (1998) that the patients also become discouraged, the survivor in this study appeared very optimistic and motivated.

Some of the research on coping with trauma or crises cited by Magwaza (1999) does not appear to hold true for the family in this study. The family's benevolence of the world and its meaningfulness do not seem to be negatively affected by the experience of stroke. There appears to be a general frustration with social ignorance about the illness and how society has reacted to the family in general, but this does not seem to have affected their overall perception of the world. The family, however, appears to have isolated themselves from society and the "world" due to the patient's condition and it is possible that as the condition progresses and the family slowly rejoins the world, clear and perceivable patterns will emerge. The assertion by Magwaza (1999) that when people experience trauma or crises their feelings of self-worth remain unaffected, however, appears to hold true for the patient and the family in this study. Both the patient and the family appear to have a general positive sense of self-worth and a general optimistic outlook on the world.

With regard to the theory that has been employed in this study, systems theory, it is clear that the family operated as an open system, and each family member and the whole family as a unit reacted to and responded to the inputs into the system and also had interaction with their environment. The inputs into the family system were acted upon and modified by the family. This process is clearly defined by how the individual family members describe the process of role redefinition and the personal sacrifices in order to sustain the family as a new unit of interaction. There appears to be an exchange of energies and information between the family and its environment and the behaviour of each family member also seems to be explained in terms of the individual member's relationship with the environment and the member's function in the family. The family has responded to the input about their new family environment after the stroke and has thus accordingly adjusted their roles, responsibilities and expectations. This finding is in line with Jones' (1993) view of family functioning.

When using the systems model of stress, the ABC-X Model of Family Crisis, to evaluate the family's process of recovery in this study, it appears that the family has negotiated the pre-trauma phase, acute coping phase, and the recovery stage successfully. The family was, however, non-committal about their status with regard to the angle of recovery. Based on each family member's account of their experience of stroke, different individuals experienced this stage with varying degrees of ease or intensity. According to the patient, the whole experience is a "process" and thus appears difficult to quantify and even to delineate precisely. The whole family, however, appear to still be in a process of negotiating their way towards finding a *new normal level*, which according to Clark (1999), is the final stage in the ABC-X Model of Family Crisis.

This study was phenomenological in nature and one of the core themes of this method of research is the "bracketing" process, where the researcher "brackets" out any information he/she may have about the research topic. If this study is then to be described as the experience of stroke as it presented itself to the awareness of the participant family members, then the study represents a narrative of a family in the midst of change versus conservation. It also illustrates how individual and family dynamics hinder or assist this process. There is a constant battle between family identity, individual identity and at a macro level, social identity.

The family underwent a process of redefinition and the whole experience, including that of the stroke as a "thing itself", was characterized by overall frustration and uncertainty. The experience of stroke for the family also speaks of loss of individual, family and social independence in order to maintain the integrity of the newly formed "family". The whole process of the family's experience of stroke speaks of constant adjustment and the challenge to personal and family belief systems in order to sustain a voice of hope and verbalize the individual and united fears about the family's current situation and what the future may entail for them.

Going back to the literature discussed in this study, it is important to acknowledge the possible impact that the researcher may have had on the data collection process. The interaction with the family members and the data itself influences and can be influenced by the researcher. According to the theory of cybernetics of cybernetics or second-order cybernetics, the observer of a system becomes part of, or a participant, in that which is being observed. The results of this study should therefore be seen in the context of the intention of the researcher. The research was intended to be a case study and exploratory in nature, and if the assertion by Fourie (1996) that research results are "constructed", instead of "discovered", is to be considered valid, then the hope of this study is to stimulate open dialogue and curiosity around issues surrounding stroke patients and their families and not to discover the "truth".

Stroke is a serious and significant health problem, which has ongoing and lasting effects not only for the sufferer, but also for the individual family members and for the family as a unit. Dialogue around the experiences of stroke patients and their families can hopefully lead to a critique of this study, and to further research related to this issue. This can eventually lead to better rehabilitation programmes that cater for individual family needs and hopefully also lead to a situation where the same curiosity and vigor with which an illness such as stroke is examined, will filter into support networks for families once patients go home.

CONCLUSION

Phenomenology as a discipline, attempts to discover and account for the presence of meanings in the stream of consciousness. It is a discipline that tries to sort out and if possible find ways of conducting qualitative research (Giorgi, 1985). Phenomenology is a philosophy initiated by Edmund Husserl at the beginning of the twentieth century with the aim of establishing a secure basis for knowledge. Husserl's starting point was the problem of how objects and events appeared to consciousness (Smith, 1995).

Phenomenological research emphasizes the lived experience of not only the research participants, but also that of the researcher. In the case of research participants, the lived experience is that of the phenomenon being studied, but for the researcher the lived experience is a process of phenomenological procedure itself: the methodological travel between description, reduction, and interpretation (Merriam, 2002). This was true for the researcher in this study.

The world is neither true nor false, meaningful nor valuable. It takes meaning only in relation to a mind that orders and relates its parts (Edie, 1987). The research method employed in this study and the theories used as lenses to observe and interpret the data in this study are therefore yet one way of looking at the world. This research does not purport to describe the ultimate "truth" about the experiences of stroke of a particular family. The research findings are just another way of dialoguing about the phenomenon of stroke and how a particular family experiences it at a specific time in dialogue with a specific researcher. It should also be noted that the family in this research volunteered to participate in the study, which might mean that they are different from other similar families in that respect. The interaction of the family with the researcher and the interaction of the researcher with the research data are also seen as subjective processes and circular in nature in that all the variables, including the family, the researcher and the data collected in this study, are constantly affecting and being affected by each other in the research process.

This study is a narrative of a family's experience of stroke. According to White (1997), expressions of life are expressions of lived-experience that are shaped by the meanings ascribed to the experience and by the practices of life and relationships that are associated with the meanings. He further argues that although the meanings that are considered in the shaping of expressions of lived-experiences are inevitably historical and cultural, they are not strictly determined. According to White (1997), there exist multiple and competing systems of understanding life and its worth, and that the fixing of meaning is an achievement that is arrived at through personal and community acts of negotiation. Meaning is then determined in the social domain of life and the contesting of meaning

becomes a feature of this domain. Based on this account, persons are active participants in shaping their own lives, and of the lives of others.

Stroke is a prevalent condition that accounts for a significant number of worldwide fatalities annually. The aim of the study was to explore this phenomenon at a more intimate level and possibly to give a "voice" to the people who usually disappear in the many statistics and to create an opportunity to give a view of stroke from a subjective perspective as opposed to the voluminous information available on the pathophysiology of stroke. It is the belief of the researcher that this was achieved. Systems theory was selected as a way of contextualizing the study and as a lens for looking at the research data. The research method in itself *(phenomenological research)*, however, provided most of the structure of analyzing and arranging the research data and the research results.

The family responded to the input into the system and their behaviour was modified by their interaction with their environment. The researcher also influenced and was influenced by the interaction with the family and the research data.

It is the hope of this study to provide yet another domain of debating meaning, in this instance, the meaning behind a family's experience of stroke. As mentioned before, this research was explorative in nature and of case study format and thus cannot be generalized to other populations or groups. The nature of the research *(phenomenological method)* makes duplication of the study impossible, but taking into consideration the nature of the data collected through this type of study, the intention is not to provide a platform for replication, but to create dialogue and more curiosity around the subject under study and the method of study itself. This study is thus part of a larger process of understanding the meanings attached to experience and is not a destination in this field of research. It is also part of the researcher's process of acquiring skills that resonates with her area of interest and training.

Appendix A

INTERVIEWS: PART I (Husband and wife)

I= interviewer ; W= wife ; and H= husband

I: First of all, who is part of your family?...who do you stay with?

W: You mean here at home?

I: Yes

W: Well, it's me, my husband, and the children.

I: How many children?

W: We have three daughters and two little boys…the other girl is with my parents.

I: Okay. About the stroke…when did it actually happen?

W: Ja,…it happened on the 23rd of October 2002.

I: Can I then ask you as the wife *(of survivor)*, what does it mean to you for your husband to have suffered a stroke?

W: To me, it means our lives are not that different. I mean, he needs more care than before. He also can't do the things he used to do before. His temper is also different.

I: The temper is different in what way?

W: The thing is, since he had the stroke, he is short-tempered. The things he used to do for himself, he can't anymore.

I: Things like what?

W: Things like housework, work normally done by the man in the house, you know. He can't do those things anymore and it means I have to most of that work now.

I: So, how are you coping with all this?

W: Well, with the progression of the stroke, the temper is getting better and you get used to it after a while. I mean, you learn to control your own temper.

I: For you then, as the woman of the house, how do you specifically deal with the situation?

W: Well, you get used to it. At the beginning, you of course have a lot of stress, but with advice it gets better. After a while, you get used to the situation and it becomes as though it's natural. After a while the stress goes away. You also get used to taking care of your partner. It just becomes like part of your job as a wife.

I: How long did it take you to get used to the fact that things have changed in your relationship and that the roles have changed?

W: It depends on how patient you are. I can say it took me about two months. Although it is very difficult, you just have to get used to it. With a lot of advice, you get used to it. If, however, you are not a patient person, then it is difficult.

I: Now then, tell me, what is the most difficult thing for you at the moment?

W: At the moment, I can say his loss of independence. When things are really bad, then I have to help him to bathe, go to the toilet and get dressed, you see. This is very difficult. However, when he is better, I just help around here and there.

The second difficult thing is that I cannot go and visit family or friends. You always have to be around in case he needs something, you know. You just hang around.

I also worry about him when I'm away that he may be lonely on his own. You know, he may have a lot on his mind and think too much when he is alone.

I: Well, how do you deal with this then?

W: I don't even work, you know. I'm worried that if I went to work, he will be lonely. I also worry about who will care for him and feed him. I just tell myself that I have someone in my life that is sick and he needs me, you know.

I: How are your friends and family reacting to all this, considering you don't get a chance to see them often?

W: I actually don't consider that anymore. I just tell them that "as you are aware, my husband is sick and I therefore can't make it to certain functions"… and so forth. I'm actually not worried about their reaction. My main concern is my family and what is happening here.

I: Do you feel that they understand what you all are going through?

W: Well, some of them understand that I have my reasons but some don't.

I: Since the situation of the family has changed due to the stroke two years ago, what do you think the future holds for you all?

W: Hmmm…I feel it will just be normal like before. I mean, we are already used to how things are now and I also said, to him *(points to husband)* that as things stand, we need to accept it and hope for the best. If, however, things don't change, we also need to accept that.

I: According to you, when you think about your situation, do you feel that there was a reason for this happening to you and your family?

W: Well, not really. We wondered why it happened. We've heard that stroke is caused by high blood pressure. He *(husband)* had problems before and we were surprised when it happened. We just accepted it eventually.

I: Some people believe certain things happen for certain reasons and some believe things happen at random. What is your belief?

W: Actually, we are still unsure. Some people will tell you this and some will tell you that so we also don't really know why it happened.

I: So tell me, for now, with you being a mother and a wife in the family, what is your biggest fear?

W: You mean about this illness?

I: Yes

W: Well, I don't have a lot of fears now. I mean, the stroke did not kill him and after the incident, we have had a chance to talk about it. He *(husband)* also has had a chance to sort out some unfinished business. We now believe that if God decides to take him, at least he will die with a light heart…having sorted out a lot of things.

If God also decides to let him live, it is also fine. What we have noticed now, is that he is getting better and we see improvement so we have hope that he will improve.

I: So, if the stroke never happened, do you feel there would be a difference in your relationship with your husband?

W: Hmmm…Well, it would still be the same I think. It's just that he *(husband)* feels that if he had not suffered from stroke, he would have done this and that. He had plans you see…but I feel it would be the same. He feels he had plans, you see, and these have not materialized. I, however, feel nothing has changed. It's the same…it's the same.

I: As far as the children are concerned, how do the feel this has impacted on them?

W: Well, Ja…now, they understand. Before, they did not understand. All they could see was that their father was now aggressive and short-tempered. But as time went on, they started to understand.

I used to tell them that their father was a strict person and he likes things done a certain way. I would explain that this is not because of his illness, but because that who he is. The illness just made it worse. They now understand.

I: What about your relationship with your husband has been affected?

H: You mean our relationship?

I: Yes.

H: We now know each other very well.

W: Yes, we are very close. I now worry a lot when he goes to work and he doesn't come back at the time he's supposed to, I worry. All those memories from before come back. I start thinking it's getting late and he is supposed to be home!

I: Can I ask you then, what about you as a person, what qualities, enable you to have such patience and acceptance as opposed to other people who may not?

W: People are not the same. Some people do not have the patience or strength to go through something like this. So, if you do not have the qualities, you need to learn patience and all those qualities you don't have. Sometimes people get angry if someone they love who has stroke is demanding. They feel overwhelmed. If you know your partner is sick and you say you love them, then you just have to learn to be patient. Even if he makes you angry, just remember that it is due to the illness. You should remember that before, he was not like this and his behaviour is due to the illness.

If you know that you don't want to assist the person when he needs your help, this also emotionally hurts him. He also starts losing hope and starts feeling like now that he is sick, he is useless.

I see that my husband appreciates my efforts. He has said from his mouth that he appreciates the support I have given him through his illness. Even his friends comment on the difference a supportive partner makes. So I try, although sometimes I'm under a lot of pressure, I try not to show it. You see, I try not to show the pressure cause when you do show, then the other person starts worrying and feeling like they are a burden.

I: If I were to ask you about stroke before your husband had a stroke, how would you describe it then?

W: Eei! I wouldn't know how to explain it then. Now that I've seen what it is like, what it does to the sufferer and so forth, it's different. Before, I would hear that someone suffered a stroke and I would see them limping.

I: What did you think of those people then?

W: I thought they were disabled you know. That's how I treated them. Many people feel that when you have suffered a stroke, then you crazy.

I: If I had an opportunity to introduce you to a family now, whose father/husband suffered a stroke, and they are still at the initial stage of the process and they don't know what is happening and to what to expect, what would say to them?

W: Actually, I would help them a lot you know! I would help them a lot! Especially the wife…well, the man also. I would help not to lose hope. Even when my husband was hospitalized, I would talk to other patients and say "you see my husband's condition now, it was bad before, so don't cry cause if you cry, you are only stressing yourself. When you are always crying, it takes a lot of energy".

I would help the wife on how to handle and cope with her husband. I would tell her to be patient. Some women, you know, lose their patience. You know that a stroke patient cannot always say I'm hungry or so forth. You have to learn their routine. You prepare them breakfast in the morning, ask if he needs water and so forth. Although he may not know how to talk, he will let you know in another way or you just leave it there. Even if they can't talk, you can ask him and he will let

you know he needs to go to the toilet. Just be patient, because if you are impatient, he can also feel you are impatient.

I: On that note, how has his language difficulties affected you?

W: Eish! That really affected us, you know. Sometimes he tries to say something and he can't say it properly. Then I just speak to him, or sometimes you can see what he is trying to say and you take the lead and ask him "do you want to say this and this?"

I: What happens when you guess incorrectly?

W: Well, then you see he gets really angry and short-tempered. I just continue to talk to him and tell him to relax and that he will remember what he wanted to say. This is because he sometimes forgets what he wanted to say, you see. One shouldn't get impatient when he does not remember what he wanted to say because he then gets angry, short-tempered and aggressive.

I: In future, if your husband stays the same, what does it mean for you?

H: We are very motivated…we want to raise our children so they have a better future.

W: …and become independent.

I: So, at the moment, do you feel the crisis has passed?

H: So far, partially, it has passed.

W:…That's what we tell ourselves.

I: Are you anxious or not about possible relapse or change in your *(husband)* condition?

W: No,…no, we are not. As far as we are concerned, he is getting better. Like I said before, I have a tendency of worrying still, especially when he goes to work and it takes him a while to come back home. I worry that maybe he will fall sick or something, but otherwise, we are fine.

H: …You know, when you have suffered from a stroke, you need to tell yourself that it has happened and it is in the past, you see. Because, you can't really say "why did it happened to me?". Whom then do you want it to happen to? To whose child? What happens, happens! It's God's will. You must just admit that this has happened that way.

I: So far, for you *(husband)*, what does it mean to have suffered a stroke?

H: What it means is that my wife has to be responsible for most things and be a wife and husband in the family. I cannot do most things so she has to also play the role of the man of the house. There is no place for feeling sorry for yourself.

I: How is it for you now that the roles in the family have changed?

H: You know what? This thing *(stroke)*, I have told myself that what has happened has happened and unless I have a chance to improve, this is my situation. If I improve, it's fine. I just need to worry about my life now, so I can be free, and take care of my life and the children.

I: According to you *(husband)*, how long does it take to reach acceptance?

H: It differs. Some people take a while, while others are in denial until they die.

I: They don't accept?

H: No, they don't accept.

W:…From what we heard, some people take up to 5 years to accept. I feel my husband is better than those people, although they are older.

I: Do you have information about stroke, or did you seek information when it first occurred?

H: The truth is that people say they understand what stroke is and what causes it, but the information is different. Some say this is this and others say that.

I: So, the information that you have about stroke, has it been from you life experience?

H: As far as I'm concerned, if I ever improve, I will be able to tell you that this and this and this happens. At the moment, I'm in the process of recovery.

W:…He will be able to say what helped him.

H: Yes, and I can come to some conclusions, and so far, at the moment I'm in a process. Once I complete the process, I will be able to say more. I will also be able to say which doctor helped me.

I: What is the importance of you being on medication?

H: Yes, it is important, to a point. Usually the pills are not the same. I take a number of them. The thing is that doctors themselves don't explain the

medication clearly. They tell you that stroke is caused by high blood pressure but they don't explain what all the medication is for.

W: …Ja, you know, he just takes the medication and we never know what it's for and if the problem that requires him to take the medication, is controlled or not. They never check him. Before my husband had the stroke, he suffered from high blood pressure and took two types of pills. But since the stroke, he takes more pills but we don't know why. Some of the pills are for cholesterol, and cholesterol is controllable and needs to be monitored.

I: Is he being monitored now?

W: No! When he goes to the doctors for a check up, they ask how he is doing, and he says there is ringing in his ear. This is also a result of the stroke. He tells the doctor, and he prescribes painkillers and that is it. He never explains what the medication is for.

I: So according to you *(husband)*, as a stroke survivor, what is the most frustrating thing?

H: You know, usually people see you like this *(points at himself)* and they pity you. This makes me feel small.

W:…Ja, you feel like your condition is worse than you thought. When people pity you, you feel you are worse off than you are.

I: Is it difficult to accept pity from people or co-workers?

H: No, not really. I think I have moved past that.

I: So, how has it been for you since you went back to work?

H: Well, so far, the department I'm at there are no problems. The thing is that I just need to wait and see. Maybe I will need to move to another department.

I: How is it like being back at work?

H: Well, I cannot talk for other people but for me, I know my work. I've always known my work and no one can dispute that. At the beginning, when I had the stroke, they *(colleagues)* thought I forgot my job. It's just that I couldn't talk and I couldn't explain myself. I, however, I know my job inside and out.

I: If someone were to ask you what it is like to try and say something and not be able to, what would you say that is like?

H: Ja, well…it's frustrating, it's really frustrating.

W:…If he wants to say something and he can't, hey! He gets really frustrated.

H: You know, if you want to say something and something else comes to the tip of your tongue, it's frustrating. When there is more than five things, then it's really difficult.

W:…If sometimes he wants to say something and it's gone from his thoughts, you need to be patient.

H: Ja!

W: I just tell him to relax and it will come back. Usually it does. If, however, you put pressure on him to remember, he becomes frustrated.

H: Ja, you know, like when we are in a meeting, I just keep quiet. I can sometimes hear what they are saying is wrong, then I raise my hand and tell them. If I can't say it, I write it down because I can't just keep quiet just because I'm a stroke survivor.

I: Do you find that your colleagues still respond to you like before?

H: Well, they don't have a choice. They have to. If they take a decision, I have to be involved.

I: So, how would you explain your situation at work?

H: I am adjusting, but there is a problem with some people who want me out of my position and they use my condition as an excuse.

I: In your family context, has your role as a father changed?

H: No, when I don't like something, I say so to the children. I even tell my wife. My speech has improved a lot, so they *(the children)* know that nothing has changed.

I: So, to conclude, if someone were to ask you what you learnt about yourself through suffering the stroke, what would you say?

H: Like I said before, this is a process and I feel I'm still in the process of recovery. Once I complete the process, I can be able to say something about that. So far, I can't really say.

INTERVIEWS: PART II (Two daughters D and S)

I: Which one of you is older?

D: I'm the eldest and she *(points at S)* is the youngest.

I: When did you start living with your parents?

D: Since last year.

I: Where were you *(points to both)* staying before.

S: With our grandparents.

I: So, at what level of your father's condition did you guys move back home?

D: When he was still in rehab. Then, he only came home for weekends.

I: So, for the two of you, if someone were to ask you what is stroke is, what would you say?

D: I would say it's a painful condition without any hope of full recovery. This is a painful condition!

I: So, is this how you see your father's condition?

D: Yes, but I hope he will get better and better.

S:…I agree! Before, he was really bad, but now he has improved.

I: Is the difference very significant?

S: Yes, initially, he couldn't walk properly, eat or talk or even use his hands. So yes, he will get better.

I: So, what was it like for you at the beginning when your father first came out of hospital?

D: Well, sometimes we didn't understand. When he had temper tantrums and outbursts, we did not always understand.

I: So, is he *(your father)* very different from when he first came out from the hospital?

Both: Yes

I: So, what is your *(both)* role in the family now?

D: At night, we massage him and we help him to do his physiotherapy exercises.

I: Is it easy for both of you? I mean, you are both young?

D: Well, we have patience. It's not really difficult to do.

I: When you look at your life, compared to friends your age, is it different?

D: Yes, it is different! Our father does not go out much, so we have to be around and help him. They *(friends)* do not do it in their homes.

S:…We also can't go to town as a family anymore.

I: So, do you feel you are missing out on quality time together as a family?

D: Sometimes I feel like that. Sometimes I wish we can go out for some fresh air, but he can't.

I: The young children, do you think they understand what is happening?

D: No, not really. But if they are making noise and you tell them, they keep quiet. We also ask them to go outside to play.

I: So, if someone were to ask you now what stroke is, what would you say? I asked that before but I want to know this from an everyday basis, what it means. What I'm actually asking is this, if I were to bring children to you whose father has recently suffered a stroke, what would you say to them?

D: I would say they need to have extra care and attention, and that they need to get used to the situation.

I: What is the most difficult thing to get used to?

S: The short temper and his language problem. Sometimes he gets so frustrated when he wants to say something that it looks like he is going to cry.

D:…We also need to think on our toes in order to find out what he wants to say.

I: What happens when you can't think of what he wants to say?

D: Then I feel bad. He usually says that he will tell you when he remembers. Sometimes he has difficulty talking because his jaws seem tired. He usually rubs them *(jaws)* a lot.

I: Do you think people understand what stroke is?

D: Ag! Some people don't understand. They think the person is crazy. When they talk to him, they talk as if they are talking to a small child.

I: How do you feel about that?

D: Sometimes, I feel like stopping them because I know he *(father)* does not like it. Sometimes people come and tell him how bad condition is, while he feels he is

actually improving. He sometimes thinks he is improving and they tell him otherwise.

I: What is it like to explain your father's condition to other people?

D: People just generally ask about my father's well-being and his progress, and that's what I tell them.

(The young children enter the room. The older sister explains that one of them is her son and the other is her brother. The children are then asked to go outside to play).

I: What do you *(both)* think about your parent's relationship at the moment and how they are dealing with this?

D: They are close now. They spend most of their time together because my mother cannot leave my father behind.

I: So, do you go out as a family?

D: No, usually someone has to stay behind with my father.

I: Did you use to go out as a family?

S: Yes, we do miss that.

I: So, from your side *"D"*, you said at the beginning of the interview that you think this condition does not look like it will change. What do you think will happen if it doesn't change?

D: Well, it's really something we are getting used to. All we are waiting for now is for him to get better.

I: What about you *"S"*, how do you feel about this?

S: I feel things will go back to how they were before.

I: So you are hopeful?

S: Yes.

I: And if the condition does not change?

D: Then we need to get used to the condition.

I: What is the process of adjustment like for you and what does it entail?

D: Well, my mother sat us down and explained everything to us before my father came home. She also asked us to be patient. So, in that way, we learnt to adjust. It took about 2 weeks to adjust.

I: And what about you *"S"*, what has the process been like for you?

S: Eeish! It took me longer to adjust. It took me about 2 months. Firstly, we had to adjust to the language problem, and then something comes up, like the short temper and then there is something else.

I: So, is it a constant adjustment?

S: Yes.

I: So, what have the both of you learnt out of the whole process?

D: To be patient and to think on our feet.

I: Is there anything you want to add?

Both: No.

I: Something I didn't ask you, how is this affecting your social lives…like boyfriends?

S: Well, that, we have excluded from our lives.

I: Is this because of your father's condition?

D: Yes, it is something new and we are learning to adjust.

I: What has this part of the adjustment been like?

D: Sometimes it's been very hard because we have friends who invite us to parties and sometimes we can't go.

I: So, all in all, would you say you *(both)* are adjusting and coping with the situation.

Both: Yes.

D:…We understand and we are coping and adjusting.

Appendix B

<u>LETTER OF CONSENT</u>

I (full names)………………………………………………hereby give consent to participate in the study conducted by Miss F P Mbatha. I understand that the information gathered through interviews will be used for research purposes. I also understand that identifying information will not be used and thus I will remain anonymous throughout the study.

Signed……………………………………..   Date………………………

Witness:………………………………..

<u>LETTER OF CONSENT FOR USE OF AUDIOVISUAL MATERIAL.</u>

I (full names)………………………………………………hereby give consent for the use of audiovisual materials in the study conducted by Miss F P Mbatha. I understand that the information gathered through interviews by this means will be used for research purposes. I also understand that identifying information will not be used and thus I will remain anonymous throughout the study.

Signed……………………………………..   Date………………………

Witness:………………………………..

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