

https://dspace.org/

# Caregiver experiences and perceptions of the effects of stroke on the family within the South African context

**Felemengas, Mary**

**2006-02-14**
http://hdl.handle.net/10539/185

Downloaded from a DSpace repository. https://dspace.org/

# CHAPTER 1: INTRODUCTION

The prevalence of stroke is growing in South Africa, particularly in the more rural areas (The SASPI Project Team, 2003). Therefore, a growing number of people are being affected either directly or indirectly by this condition, and the perception of stroke as a first-world disorder is being increasingly challenged by recent findings. The onset of a stroke results in enduring changes in the lives of caregivers of stroke patients as well as their respective family members (King, Shade-Zeldow, Carlson, Feldman & Philip, 2002), as the dynamics within the caregiving process are complex and multivariant (Bakas & Burgener, 2002). The present study investigated these issues through the administration of a semi-structured interview with six primary caregivers, in order to uncover the family dynamics within the family system, as well as how these have evolved or changed following a stroke. Systems theory provided the foundation on which these experiences were assessed, as this model directs our attention toward the relationships and relationship issues between individuals (Becvar & Becvar, 1996). A biopsychosocial perspective, which adopts a systemic orientation and is in essence a systems theory, enabled individual experiences to be considered holistically whilst acknowledging the influence of environmental factors.

Results from the present study indicate that prominent themes associated with the challenges of caring for a stroke patient include: relationship disruptions in the family system as the period post-stroke was perceived by most participants as one of adjustment; role changes particularly in cases where the caregiver was the child of the stroke patient; high levels of fatigue due to the strenuous tasks involved in the caregiving role; anxiety and depression and social and

occupational implications, as well as financial problems. Participants found that the emotional impact on the family system was greater in cases where the stroke patient had young children, as the stroke resulted in a disabled parent and thus a change in the dynamics within their family system, which required a large amount of adjustment for all involved. However, social support in the form of psychotherapy as well as practical and emotional support from extended family and friends increased the caregivers' ability to cope. The only inconsistency with the above themes involved one participant who did not perceive the caregiving role to be of any challenge, but rather one that she performs out of a sense of duty, and this could be due to her cultural ideals as her ethnicity differed to that of the other participants. However, a multitude of factors could have come into play, such as coping styles and personality traits, as these factors may influence one's perception of caregiving as well as one's ability to cope with the adverse conditions associated with this role. The other five participants found caregiving to be challenging. Taxing areas for these caregivers could be categorised into biological, psychological and social dimensions that affected them and their respective family systems. Furthermore, these experiences were exacerbated by the inadequate support structures available for caregivers within the South African context, in the form of post-stroke advice from medical practitioners in government hospitals as well as the lack of referrals for psychological care, thus failing to provide multidisciplinary treatment for stroke patients and their caregivers. The lack of post-stroke education and information was a pressing issue for most of the caregivers in the present study, having serious ramifications as it hindered their ability to provide the appropriate care to their stroke patients.

As there is insufficient research conducted in South Africa concerning caregivers and their experiences of caregiving, this study provides unique information in this particular area of research, in terms of its interpretive perspective and local focus. In this way, it is beneficial and significant to caregivers as well as families affected by stroke. In addition, it highlights particular gaps within the psychomedical system that are in need of attention and further development. Addressing these issues would result in enhanced stroke patient care due to the increased knowledge and coping skills of caregivers which, in turn, would have a positive impact on the rest of the family system thus facilitating their period of post-stroke adjustment.

In order to understand the fundaments of stroke and its effects, this research report begins with a brief discussion of the definition and types of stroke before embarking on the theoretical framework which underpins the present research. Chapter 3 provides an extensive literature review in the area of stroke covering its prevalence and effects, whilst chapter 4 illustrates the methodology employed in the study. The final chapters state the results of the present research along with a discussion, and conclude with chapter 6 which highlights the limitations of this study and provides suggestions for further research in the area.

## 1.1 Definition and types of stroke

A cerebrovascular accident (CVA) is the most frequently encountered of the cerebrovascular disorders and is commonly referred to as a stroke (Lezak, 1995). A CVA consists of a heterogeneous group of vascular disorders that result in brain injury. To put it quite simply, it "… suffocates brain tissue and produces an area of dead or dying brain tissue" (Zillmer &

Spiers, 2001, p. 301). Most cases of cerebrovascular disorders are caused by cerebral ischemia (a deprivation of blood supply) or haemorrhage (Walsh & Darby, 1999). Therefore, the two mechanisms that are responsible for the tissue starvation of CVAs include: obstructions of blood vessels resulting in an ischemic condition, whereby a disturbance or absence of blood flow takes place; and haemorrhage. In reality these two mechanisms can not be considered entirely separately and this is accountable to the fact that some obstructions are hemorrhagic in nature, whilst some haemorrhages bring on spasmodic constriction of the blood vessels (vasospasm) resulting in focal sites of obstruction (Lezak, 1995).

Having mentioned the mechanisms of stroke, the succeeding section expands on the different type of strokes.

### *1.1.1 Cerebral thrombosis*

In thrombolic strokes the infarction is as a result of the occlusion of a blood vessel by a clump of blood particles and tissue overgrowth (a thrombosis) that form where blood vessels branch, or on lesion sites on the vessel wall. As the thrombosis grows, so the opening of the blood vessel narrows, decreasing blood flow or alternatively closing the vessel altogether. These strokes may occur suddenly, but generally take up to half an hour to develop. In 50-80% of cases they are preceded by a transient ischemic attack (TIA), little stroke, where symptoms may disappear within a day (Lezak, 1995).

### *1.1.2 Cerebral embolism*

Approximately 20% of obstructive strokes are embolic. Obstruction in these strokes is a consequence of an embolus, a plug of thrombolic material or fatty deposit broken from blood vessel walls, or of foreign matter, such as obstructive gas bubbles. A limited amount of thrombolic emboli develop from lesions within the major arterial pathways to the brain. Most develop outside the intracranial circulatory system, namely, in the heart and blood vessels. Embolic strokes tend to have an abrupt presentation, without warning precursors, such as a headache or TIA. Embolic strokes are commonly associated with heart disease and tend to occur at an earlier age than thrombolic strokes (Lezak, 1995).

### *1.1.3 Haemorrhage*

Haemorrhage is the primary agent of damage in 10 to 20% of all strokes (Powers, 1990), with hypertension the chief precipitating factor. Hypertensive hemorrhagic strokes frequently occur in people aged 60 to 80, whilst younger people are more likely to experience ruptured aneurysms (Lishman, 1987). The two common mechanisms causing arterial rupture include: the weakening of a vessel wall as a result of pathological alterations secondary to hypertension, and ruptured aneurysms (a weak vessel wall which balloons out and eventually bursts under pressure) (Walsh, 1985). It is relatively rare to have warning symptoms preceding ruptured aneurysms (subarachnoid haemorrhages); however, the patient may experience painful headaches along with nausea, vomiting and neurological dysfunction. Depending on the severity of the bleed, the intensity, as well as site of vasospasm, the patient may or may not

lose consciousness. An important contributor to ischemia and to the mechanical pressure on brain structures leading to tissue damage is elevated intracranial pressure. This condition may be fatal; however, if the bleeding is addressed quickly the patient may sustain few cognitive deficits and limited brain tissue damage (Ogden, Mee & Henning, 1993). In cases where damage is extensive but not fatal, patients may display behavioural impairments attributable to focal damage (Lishman, 1987).

A third source of hemorrhagic strokes is arteriovenous malformation (AVM) a mass of arteries and veins of congenital origin which grows similar to a tumour (Brown, Spicer & Malik, 1991).

### *1.1.4 Transient ischemic attacks (TIA)*

TIAs are episodes which involve a temporary obstruction of a blood vessel, and by definition last less than 24 hours, however, many last for only a couple of minutes (Levy, 1988; Mohr & Pessin, 1986; Werdelin & Juhlur, 1988; cited in Lezak, 1995). Their presentations follow similar patterns to that of a stroke and are characterised by mild stroke like symptoms. Like strokes most TIAs are associated with arteriosclerotic disease and generally have small infarctions from thrombotic microemboli that move on before resulting in much damage. Patients may have several of these attacks either relatively closely spaced or over an extended period of time (Lishman, 1987). Approximately 25 to 35% of patients who experience a TIA eventually sustain a major stroke (Powers, 1990).

### *1.1.5 Silent Strokes*

Silent strokes are small lesions situated in deep brain structures that generally go unrecorded; however, a study conducted by Chodosh, Foulkes & Kase (1988) revealed that 11% of a large sample of subjects had suffered this type of stroke without any knowledge of it. Left hemisphere silent strokes are most likely to be unrecorded when they are small and in deep structures in the brain, whilst right hemisphere silent strokes tend to be larger with a greater likelihood of involving the cortex. CT or MRI scanning usually identify the occurrence of silent strokes, alternatively the stroke is picked up when the patient seeks medical attention due to behavioural changes (Lezak, 1995).

This study focused on the first three types of strokes discussed, namely: cerebral thrombosis, cerebral embolism, and haemorrhages; as they require greater care post-stroke, and as a consequence result in challenges for the caregiver and family. The biological as well as psychosocial ramifications of stroke will be addressed in chapter 3; however, the next chapter focuses on the theoretical framework which provided the foundation for this research.

# CHAPTER 2: THEORETICAL FRAMEWORK

## 2.1 Systems Theory

First-order cybernetics or general systems theory is a rather radical departure from the Newtonian-Cartesian epistemology, which governed the field of psychology for many years, and still underlies most therapeutic models and theories in existence today. The Newtonian-Cartesian or biomedical model is based on the principles of reductionism, linear causality and realism, which are consistent with the ideals of western society. According to the term reductionism, in order to understand a complex phenomenon, such as the human mind, one must reduce it to its most basic elements. By doing this one can discover general laws or principles which are objective, absolute truths about reality. Linear causality or cause and effect thinking holds the assumption that causality is uni-directional i.e. A (the cause) is responsible for causing B (the effect); with realism embracing the notion that the world is external to the observer and this reality is objective. A criticism of the Newtonian-Cartesian approach is that it completely ignores the broader context in which the individual exists, hence the therapist treats the symptom(s) utilising predictable outcomes for all clients (Meyer, Moore & Viljoen, 1997). A further limitation of this model includes its inability to incorporate psychological, psychosocial, or spiritual factors of health which constitute a large part of modern daily ailments and stress-related diseases. Thus, failing to fully respond to the needs of our time, despite its sound scientific rigour (Eisenberg, Kessler, Foster, Norlock, Calkins & Delbanco, 1993).

General systems theory attempts to integrate and create wholes out of parts. Quintessentially, it's a science of wholeness, its principles are based on the observation that nature is organised in patterns of complexity and comprehensiveness. These larger wholes having unique characteristics that cannot be identified or accessed through the analysis of its component parts (Weiss, 1977; von Bertalanffy, 1968). This theory directs our attention toward the relationships and relationship issues between individuals. Cybernetics' primary concern is with the way in which a system is structured and what the patterns of this system are. A 'system' is a network consisting of parts that are in mutual interaction or recursively related. Therefore, each part effects and is affected by the other parts of the system. Living systems, such as families, exchange information with their environment and govern themselves through implicit rules that are specific to their system (Becvar & Becvar, 1996). Systems are characterised by:

- A degree of *openness*, which refers to a continuous flow of information from other systems.
- *Relationships* in a system: all parts interact with each other and cannot be understood independently. Therefore, to understand one part of the system, it must be perceived in the context of the whole system. A change in one part will inevitably affect or change all the other parts of the system, as all parts are interlinked and the system is a network of circular-causal links.
- *Non-summativity* whereby the whole is greater then the sum of its parts i.e. 1+1=3; as the whole is made up of the sum of its parts plus their interactions.
- *Equifinality* refers to repetitions of patterns of interactions in systems resulting in the same outcomes. The manner that systems cope with situations and how the members interact with one another will inevitably bring the system to the same point each time.

> For example, whenever the child misbehaves the couple will argue over the appropriate discipline for the exhibited behaviour, and eventually the child will not receive any form of discipline as the parents have directed their attention to their argument concerning their differing views (Becvar & Becvar, 1996).

Second-order cybernetics (ecosystemics) is an extension of the assumptions mentioned above but emphasis is placed on the active process between the observer and the observed, and therefore, involves a higher level of abstraction. This perception challenges the notion that one passively sits while the environment imprints itself on the observer. Rather, one constructs one's reality (as opposed to discovering it) and these constructions guide one's behaviour. Postmodernism purports that people experience their world on the basis of stories which are constructed through interactional experiences with others and therefore, there is the absence of belief in objective reality. This assumption of the postmodernism movement is congruent with the contribution of second-order cybernetics. Subjectivity is considered inevitable as the observer perceives and actively constructs his/her own reality; the interdependence of the observer and observed illustrates the holistic perspective of this model, where mutual influence exists in the context of their interaction. Understanding on the part of the observer requires assessing the system's patterns of interaction with an emphasis on what is happening rather than why it is happening (Ceruti, 1994).

The family system according to systems theory is examined in terms of the context of relationships in which each family member influences the other, and all parties are equal cause and effect of one another's behaviour. This is frequently referred to as a network of circular-

causal links, as communication is not linear (A to B) but works in a circular motion whereby A and B mutually interact and influence one another. Reality is not external to the individual but constructed through one's personal perceptions which give meaning and order it based on their worldview; reiterating the inevitable subjectivity and proactive existence of the individual i.e. each member of the system is influencing and being influenced simultaneously, as opposed to being passive to the interaction taking place. The traditional notion of the therapist-client hierarchy is rejected, in favour of a more egalitarian stance, aiming not to be an expert but to work collaboratively with the client for new, more empowering ways of being. Therefore, the therapist needs to avoid implying access to the 'truth' (Becvar & Becvar, 1996). When considering a family system that has been affected by stroke, as in the present study, one needs to be aware of the family's understanding of illness and perception of their level of functioning as a system. The open-ended questions utilised in the interview (see appendix A) enabled the participants to assess their own experiences and identify their system's level of adjustment post-stroke, as opposed to the researcher administering an inventory based on preconceived western ideals of family functioning and coping.

Families, like all systems, have certain implicit rules and these parameters are set by the system itself and conflict (such as a wife who is the caregiver arguing with her husband, the stroke patient) can threaten the balance of the system. Something needs to happen in order to terminate this conflict and restore homeostasis once again. Homeostasis refers to the process by which the system maintains its stability. This may result in another family member becoming symptomatic (such as the child having an acute episode of anxiety), which provides the homeostatic mechanism of this family system. Therefore, the symptom is functional in

maintaining the system (such as diverting the couple's attention from their marital problems to the child's symptoms which may ultimately prevent separation or divorce). This illustrates how families tend to exhibit specific patterns of interactions which maintain the status quo and do not allow change to occur (Becvar & Becvar, 1996). Every family member is pertinent to the functioning of the family unit as a whole, as part of a system; change to one member will inevitably affect the homeostasis of the entire family unit. This affects all the family members and culminates in a period of readjustment by each member as well as the entire family unit, in order for homeostasis to be restored (Turnbull & Turnball, 1986b; cited in Wade, Taylor, Drotar, Stancin & Yeates, 1997); as depicted in the example above.

Due to the interdependent nature of the members within a system, an impairment of one member, such as suffering a stroke, has a vast impact on the other members within the family system (Turnbull & Turnball, 1986b; cited in Wade, Taylor, Drotar, Stancin & Yeates, 1997). Coping styles will vary for each family member and generally range from active and concerned involvement towards the impaired individual, to emotional detachment and distancing. The acceptance of the situation as well as the impaired individual also varies among the members. The goal is for the family to re-integrate the impaired individual into the familial unit. During this process family roles are re-defined, and it proves to be a strenuous time for all involved (Faison, Faria & Frank, 1999).

The family needs to be conceptualised as a social unit embedded in a context of other such units, from health services to communities and society (Gochman, 1988; cited in Akamatsu, Stephens, Hobfoll & Crowther, 1992). Systems theory moves beyond the individualistic

orientation, acknowledging the important role the family plays in the maintenance of health and reaction to illness (Akamatsu & Laing, 1992; cited in Akamatsu, et al., 1992) and thus provides an appropriate framework to work from when conceptualising the effects of stroke on the family.

## 2.2 The Biopsychosocial model

After the explicit criticism of the biomedical model in the late 1970s due to its somatic reductionism; an area acknowledging the holistic concept of health emerged. This new approach recognised the interaction of mind and body in illness, namely the biopsychosocial model (Alonso, 2004).

The biopsychosocial model proposed by Engel (1977) considers illness within a framework of multiple systems and is thus fundamentally a systemic model. To understand an illness one must not only attend to the biological factors (physiological processes) specific to the biomedical model, but consider the person, the family, the patient-provider relationship, as well as the social context. These elements are interrelated and thus a change in one level can affect the other levels as there is continuous and reciprocal feedback across levels. This integrative approach highlights the importance of an interdisciplinary examination covering various aspects of the individual, thereby superseding the limitations of the medical orthodoxy, which was very linear in its approach, and adopting a more systems based framework.

Within health psychology, family systems considerations have gained recognition, with Kerns and Turk (1985) highlighting the importance of interdisciplinary examination and an integrative systems model to apply research to families and health. Family health is built on the biopsychosocial model and emphasises the role of the family system in the functioning of individuals. It refers to the holistic well-being of the family system in terms of the physical, emotional, social, economic, cultural, and spiritual dimensions of the family (Pardeck & Yuen, 2001). The biopsychosocial model is more descriptive than explanatory regarding transactional influences between family and health factors, which is consistent with the goals of systems theory, namely, describing what is happening as opposed to an explanation of "truth" (Akamatsu & Laing, 1992; cited in Akamatsu, et al., 1992). These contributions surpass any confluence that one perspective can offer; taking cognisance of the powerful situations (such as medical conditions, treatments, and health care systems) that interact with the family system (Kazak, 1992; cited in Akamatsu, et al., 1992).

Due to medical advances in recent years thousands of victims of trauma and severe illness who previously would have died have survived. However, one of the consequences of this revolution in medical technology is a large increase in the number of families who are now responsible for the long-term care of disabled relatives. It is thus critical for family researchers to learn as much as possible about the impact of chronic illness on family life so that realistic and affective methods can be developed to alleviate the burdens these families face (Jacobs, 1992; cited in Akamatsu, et al., 1992).

In order to maximise the capacity of the family's belief system to adapt to illness demands, whilst protecting the integrity of its most enduring values, an approach must be employed that identifies aspects of illness that challenge family life, as well as those aspects of family life that are most affected by chronic disorders. It is suggested that practitioners review the effect of the illness on the family and help the family mobilise its pre-existing resources (Jacobs, 1992; cited in Akamatsu, et al., 1992). A focus on the couple as an intermediate level of analysis may highlight key issues and be a crucial determinant of both biomedical and psychosocial outcomes for the patient; therefore illness in a spouse can have profound implications for married life (Coyne & Fiske, 1992; cited in Akamatsu, et al., 1992).

Engel used the principles of systems theory to develop the biopsychosocial model. His intention being, to extend the biomedical model to include the psychosocial factors that are largely excluded by the biomedical approach (Engel, 1980; 1982). Engel acknowledged that systems theory provides a conceptual approach suitable for the biopsychosocial concept of disease and medical care as interrelated processes (Engel, 1977). By integrating systems theory and the biopsychosocial model one is able to identify and explore the experiences of the caregiver and family, working from a comprehensive and interdisciplinary perspective, as opposed to adopting one approach that may be flawed with limitations and fails to tap into the vital issues this research aimed to investigate.

# CHAPTER 3: LITERATURE REVIEW

## 3.1 The prevalence of stroke in South Africa

With the life expectancy of people being greater than in the past, people are entering age groups that are at a higher risk of strokes; and there is thus an increasing prevalence of this disorder on a global level (Zillmer & Spiers, 2001). The prevalence of stroke is considerably greater than those quantified due to the occurrence of 'silent' strokes that fail to have obvious motor or sensory ramifications, and thus remain undetected (Wiebe-Velazquez & Hachinski, 1991; cited in Lezak, 1995). According to Statistics South Africa (2002) cerebrovascular disease is the leading cause of death among persons aged 50 and above, for both genders; accounting for 8.9 % of male deaths and 12.7 % of female deaths in South Africa. One of the greatest causes of stroke is hypertension. Stroke "… affects black patients as badly as white patients, unlike heart attacks which are more common in white patients" (Fritz & Penn, 1992, p.1). Therefore, strokes are reasonably prevalent within this culturally diverse context. For many years the prevalence of stroke has been well documented in high-income countries with recent review studies ranging from 461 to 733 per 100 000 for people above 65 years of age (Feigin, Lawes, Bennett, & Anderson, 2003), but it has only recently been emphasised as an important cause of death and disability in low-income countries, like South Africa. Therefore, there is limited literature available on the burden and nature of stroke in sub-Saharan Africa (The SASPI Project team, 2004).

The Southern Africa stroke prevention initiative (SASPI) is a multidisciplinary research initiative that was prompted by the high stroke mortality in a rural area in South Africa, which has been monitored by a health and demographic surveillance system since 1992. The pilot study utilised triangulation (multi methods) to address stroke in rural South Africa, and was conducted in Agincourt 500kms northeast of Johannesburg, an area of 400sq km consisting of 21 rural villages.

The study involved census workers asking household informants 2 screening questions for stroke during the annual census. If either question was answered positively, a clinician visited individuals aged 15 or above. Seventy four percent of the 982 positive responses to the questionnaire were examined to confirm the possible diagnosis of stroke. Stroke was defined according to the World Health Organisation criteria and a detailed assessment was carried out. Results revealed a crude stroke prevalence of 243 per 100 000 which is higher than previously reported in rural Africa, with more than 80% of the survivors hypertensive or with organ damage as a result of hypertension. This is surprising as there is usually a lower prevalence of hypertension in rural settings; however, this is growing rapidly. Only one individual (of a sample of 103) was adequately controlling his or her hypertension through medication, although most survivors sought help with their symptoms from both allopathic as well as traditional healers. Furthermore, 66% of the stroke survivors in the study needed help with at least one activity of daily living, be it washing, dressing, bathing, feeding, movement, or toileting. This illustrates how the burden of caring for the stroke patients rests with their immediate family, which impacts on the employment or education of family members.

Accessing pensions and disability grants served to be important for coping with the burden of caring for the patients as well as household survival (The SASPI Project Team, 2003).

Studies have indicated the significance of hypertension as a risk factor of cardiovascular disease as well as the lack of prophylactic treatment. The etiology of hypertension in rural areas of South Africa has not as yet been established and further investigation is required before primary prevention interventions can be implemented. If a health service intervention is to be effective its approach needs to be multidisciplinary i.e. involve private doctors, traditional healers, churches, and provincial health services (The SASPI Project Team, 2003).

In summary, South Africa is currently attempting to overcome serious tribulations such as HIV/AIDS and other diseases associated with poverty and violence; whilst now facing the additional challenge of adapting its health care systems to accommodate the increasing epidemic of vascular disease. An additional concern is the association between HIV infection and stroke (Mochan, Modi & Modi, 2003) hence the suspicion of HIV infection in 2 stroke patients in the SASPI stroke study where there was no other detectable cause for stroke in the patients aged 26 and 42 respectively (The SASPI Project Team, 2004). Research on the correlation between HIV and stroke is still in the initial stages of development.

Not only is stroke a medical condition, but exists in a social context having biopsychosocial consequences. Therefore, when considering the effects of stroke one needs to adopt a biopsychosocial approach in order to address the various dimensions of this condition as its ramifications are far from unilateral for the stroke patient as well as their significant others.

Each aspect will be discussed in turn, namely; the neuropsychological consequences, the psychosocial consequences of stroke, as well as its effects on the family system.

## 3.2 Neuropsychological consequences of stroke

From a purely medical perspective, a stroke is a focal neurological disorder involving the decreased blood flow to and within the brain as a consequence of a pathological process in the blood vessels (Walton, 1994). The main pathogenic feature of stroke is the lack of nutrients i.e. oxygen and glucose to the brain, a result of the disrupted blood flow. With the nervous tissue of the brain incapable of surviving more than a few minutes of oxygen deprivation, irreversible brain damage commonly occurs. The disruption of blood flow (infarction), leads to a damaged area of tissue referred to as an infarct (Lezak, 1995).

Stroke predominantly has one-sided effects, i.e. the effects tend to be localised to a specific hemisphere of the brain, and these infarcts in turn affect the opposite side of the body antagonistically. There is a vast range of deviation between stroke patients in terms of depth, extent, and site of damaged tissue. However, electrological studies using CT and MRI scans have revealed that lasting alterations of functions of the brain may be distant from the actual lesion (Gummow, Dustman & Keaney, 1984; cited in Lezak, 1995). Secondary diffuse effects occur during the acute stages, and are thus considered additional symptoms of widespread brain pathology; symptoms may improve in the primary stages of the illness. These secondary effects, such as swelling, can result in serious bilateral or diffuse damage. As the swelling decreases so the bilateral or diffuse dysfunction slowly improves along with lateralised

impairments. One-fourth of aphasic (disturbance in language usage or comprehension) stroke patients regain speech fluency within six months, whilst most regain speech fluency within one month if it is to return at all (Lezak, 1995).

Site as well as size of lesion is associated with level of improvement in functioning (Knopman, Selnes, Niccum & Rubens, 1984). Most patients with hemiplegia (lateralised paralysis) regardless of the side of lesion, at one month post-stroke have perceptual deficits (Edmans & Lincoln, 1989), and 97% of aphasic patients with hemiplegia are affected by these problems. Most patients who experience ischemic strokes (temporary strokes with transient deficits) are left with lateralised deficits and minimal evidence of diffuse damage (Lezak, 1995).

Left-sided infarcts, in the majority of cases, result in speech and language disorders; their specific nature depends on the site and extent of the lesion (Murdoch, 1990); whilst right-sided lesions exhibit perceptual and visuospatial deficits (Costa & Spreen, 1985).

Thrombotic strokes emanate from atherosclerotic lesions in the internal carotid or the vertebrobasilar arteries, which lead to infarcts which generally involve posterior frontal, temporal, and parietal structures in the region fed by the middle cerebral artery; or when the vertebrobasilar system is involved. These occur in the brain stem, inferior temporal lobe, as well as occipital lobes. Approximately 80% of patients who suffer a thrombotic stroke in the region of the middle cerebral artery exhibit spontaneous improvement, however, almost half continue to be disabled, and patients with right hemisphere lesions tend to be more functionally impaired than patients with lesions in the left hemisphere of the brain (Diller, 1968; Kertesz,

1993; Pimental & Kingsbury, 1989; cited in Lezak, 1995). Cognitive disorders associated with right-sided damage include visuospatial abilities and gestalt-like concept formation; those with left-sided damage tend to be relatively aphasic (a disturbance in language usage or comprehension), with paralysis, limb weakness and somatosensory changes common in these patients. Vertebrovascular strokes situated in the structures below the cerebrum or in the brainstem effect movement, sensation, and consciousness, as opposed to cognitive functions (Lezak, 1995).

With embolic strokes the middle cerebral artery territory is the most common site, and symptoms with relatively restricted cortical damage are likely to occur as opposed to other types of stroke. With ruptured aneurysms cognitive deficits differ from ischemia stroke impairments as damage tends to be more extensive and do not adhere to neuropsychologically defined patterns (Lezak, 1995).

Haemorrhages associated with hypertension often involve blood vessels at the base of the cerebral hemisphere, thus the damage is frequently subcortical. Therefore, these strokes affect the thalamus, basal ganglia and brain stem, According to Kase and Mohr (1986) these hypertensive cerebral haemorrhages or intracerebral haemorrhages have a mortality rate of 65%. Surviving patients tend to display motor system impairments, as well as residual symptoms and memory deficits (Crosson, 1992). Patients who have experienced ruptured aneurysms of the anterior communicating artery tend to exhibit behavioural disturbances associated with frontal lobe lesions, such as Korsakoff memory disorder (Lishman, 1987).

One percent of all strokes are hemorrhagic AVMs. The cognitive effects of non-hemorrhagic AVMs tend to be mild and not reflective of lateralised damage (Brown, Spicer & Robertson, 1989).

A closer look at TIAs via neuropsychological testing and family reports reveal that TIA patients do suffer mild cognitive impairments which become increasing apparent with repeated attacks (Lishman, 1987; Walsh, 1985).

Research shows that age and gender have an influential effect on determining the presentation of stroke (Kase & Mohr, 1986). The bilateralisation tendency in women may account for findings of less severe behavioural manifestations of stroke in the female gender (Basso, Capitani, & Moraschini, 1982). However, there seems to be conflicting evidence regarding lateralised gender differences in stroke presentation (Lezak, 1995).

## 3.3 Psychosocial consequences of stroke

Apart from neurological deficits, which have been well documented, there are also psychological and social changes associated with strokes. Motor and cognitive impairments as a result of stroke have psychosocial consequences for the stroke patient, such as depression, social isolation (King, Shade-Zeldow, Carlson, Feldman & Philip, 2002), and a change in self-concept which may incite an increased level of anxiety (Ellis-Hill & Horn, 2000). Other emotional reactions to stroke include emotional lability, apathy (lack of emotions), low self-esteem, anger, and frustration (Zillmer & Spiers, 2001).

During the acute stages of stroke, individuals with left-sided infarcts i.e. people who suffered a left hemisphere stroke tend to exhibit depression and catastrophic reactions, whereas individuals with right-sided infarcts are associated with indifferent reactions (restricted emotional expression) (Gainotti, 1972; 1989; Starkstein & Robinson, 1992; cited in Lezak, 1995). However, two weeks post-stroke patients' relatives reported that depression was the primary emotional change, regardless of the side of the lesion; and the level of indifference increased significantly in patients experiencing left hemisphere involvement (Nelson, Cicchetti & Satz, 1993). Therefore, one can assume that left and right hemisphere stroke patients may experience different forms of depression. Additionally, depression has been associated with left anterior and right posterior strokes; there seems to be significantly lower levels of depression in patients whose infarcts are in the anterior right or posterior left region (Finset, 1987; Robinson, & Kubos, 1984; cited in Lezak, 1995). Patients with left posterior lesions tend to experience delusions, elation, and lack the awareness of their aphasia (Signer, Cummings & Benson, 1989).

Most of these studies have been conducted on patients still hospitalised or in rehabilitation thus in the early stages of their recovery, however, studies conducted in the later stages of recovery indicate that symptoms of depression increase in severity (Magni & Schifano, 1984). One questions whether these emotional disturbances are a direct consequence of the infarct, i.e. the fact that the integrity of the brain has been compromised eliciting a more organic etiology; or whether depression (post-stroke) is as a result of the challenges associated with this condition, i.e. the patient becomes depressed due to the poor quality of life following a stroke which

suggests a psychological basis for these emotional reactions. The latter argument is supported by a study conducted by Starkstein and Robinson (1992) whereby 30% of patients who failed to exhibit symptoms of depression on discharge became depressed later. Post-stroke depression is multifactorial in origin and commonly associated with excess disability, cognitive impairment and mortality (Whyte & Mulsant, 2002). Patients "experience a differing relationship with their bodies, their families and wider society" (Ellis-Hill & Horn, 2000, p.280). Therefore, its consequences are wide spread and include physical, social, personal and economic considerations (Fritz & Penn, 1992). The neurological and psychosocial ramifications of stroke that have been discussed, place great strain on the caregiver of the stroke patient as well as the entire family system and will be the focus of the succeeding discussion.

## 3.4 Familial implications

According to Schutte cited in Fritz & Penn (1992, p.50) "…stroke is as much an illness to the family as to the patient because the family is the patient's primary support system". The family plays a vital role as family members have to communicate with patients, work through their psychological adjustment, assist with movement, feeding and dressing, as well as being encouraging and supportive. The lack of social services and facilities in South Africa, especially in rural communities, intensify these issues, as the basic needs of the patient may not always be met, restricted by his or her socio-economic status and environment. Each family member needs to adjust to the altered situation. Counselling may be a viable option, although this is an ideal support service i.e. a luxury, particularly within the South African context.

Families of patients with severe brain injury report more stressors over time (Prigatano, 1999). This could be associated with the experiences and effects associated with severe brain injury on a biological, psychological and social level for the patient's caregiver and family. The rehabilitation process is not only costly but predominantly fails to address the needs of the family. Based on informal telephone calls made by the researcher to establish available resources for families affected by stroke living in and around Johannesburg, results indicate that psychologists are available for the family but ongoing support groups for family members of stroke patients is not yet well established. Interestingly, a study conducted by King et al. (2002) found that family functioning became less healthy following discharge; this finding reinforces the importance of continual support which is lacking in South Africa.

In order to identify the processes involved when a stroke occurs within a family various stages have been hypothesised regarding the "Illness experience" (Germain, 1984; Schlesinger, 1985) that can be applied to the context of stroke and are stipulated below:

1. **The symptom experience:** refers to the occurrence of the stroke.
2. **Assumption of the sick role:** if a person is aware of the likelihood of illness he or she can prepare him or herself and the family for the event. As a stroke is an unanticipated sudden event no preparation is made and the crisis of the illness is heightened. The patient has to relinquish normal roles. This affects the family as roles are changed and redefined in order to restore the equilibrium of the system.
3. **Medical care contact:** the patient transfers control of the condition to the physicians. This has financial ramifications for the caregiver and family.

4. **Dependent role:** the patient becomes totally dependent on doctors and related health professionals for treatment.
5. **Recovery and rehabilitation:** the patient has to relinquish the "sick" role and resume a "normal" role within the limitations of the disability. Therefore, new roles emerge that are difficult to accept. The role of the caregiver and family is vital in assisting and aiding the rehabilitation process which needs to take on a biopsychosocial approach. As the family affects the experiences of the patient so this can occur in the other direction, whereby the experiences of the family are vastly affected by the patient and their recovery. Therefore, in accordance with systems theory the individual illness experience will have implications for the caregiver and family.

Experiencing a stroke in the family proves to be very disruptive to family roles as caregiving tasks are assumed and emotions of anxiety, depression, guilt, anger, as well as resentment may be experienced by the caregiver (Hartke & King, 2002). Stroke is known to not only affect physical function but also emotion, memory and thinking, communication, and quality of life (Lai, Studenski, Duncan & Perera, 2002). However, family members describe the disturbance in the patient's communication as the most stressful and difficult factor to cope with (Van Veenendaal, Grinspun & Adriaanse, 1996). Poor communication tends to have negative effects on the patterns of interaction within the family system therefore, intensify negative experiences for the caregiver and family of the patient (Van Veenendaal et al., 1996).

Multimethod studies focusing on the caregiver's subjective experience of 123 elder spousal caregivers in the United States revealed challenges in various spheres of life, including:

emotional distress; learning new skills and assuming new roles; coping with the health care system and limited resources; relationship disruption; as well as social constraint (Hartke & King, 2002). More quantitative techniques using questionnaires as a data collection instrument indicate that family members are also reported to struggle with social isolation, behavioural problems, financial strain and sleep disturbances (Van Veenendaal et al., 1996). Malone (1964) echoes these issues and identifies nine major themes that describe the effects of stroke on the family. These include: role changes, irritability of family members, guilt feelings, altered social life, financial problems, health problems, vocational problems, rejection or over-protectiveness of the spouse caused by ignorance of how to interact with the patient, and effects on children. Sexual problems may be an additional consequence of the disability and should be addressed, as sexual adjustment counselling is an integral part of the rehabilitation process (Fritz & Penn, 1992). Loneliness, depression, and a sense of burden are three forms of distress that have been associated with negative adaptation to caregiving. Depression, the most frequently documented (Hartke & King, 2002), is reported as occurring in 34% to 52% of caregivers. In some cases the depression scores of caregivers have been higher than those of patients. Stroke patient characteristics such as stroke severity, physical impairment, patient's level of depression, as well as negative personality characteristics have been associated with the depression experienced by the family caregiver. With additional emotional distress factors being low caregiver self-esteem, high task difficulty, and high threat appraisal (Bakas & Burgener, 2002).

Spouses are the most probable caregivers and their prevalently senior age as well as health problems places them at risk for morbidities due to the stress of caregiving (Hartke & King, 2003). As stroke is a condition mainly affecting the elderly, it is likely that both patient and

caregiver are past their physical prime. Distress, anxiety and loss of income, as well as the need to take on novel tasks formerly the responsibility of the patient, reflects the burden the caregiver carries. Youngson (1987) believes that no one should be expected to carry this major responsibility without professional help or advice.

The stress of caregiving leads to emotional, physical as well as social morbidities in the caregiver; with studies confirming significant levels of depression and anxiety in this population. These emotional states have been closely associated with the nature of functional disability in the patient, as the caregiver's quality of life depends greatly on the patient's needs; the more the stroke patient can achieve alone the better their relationship, as it reduces resentment felt on both sides (Youngson, 1987). "Type and severity of stroke impairments have been variably associated with caregiver distress" (Hartke & King, 2002, p.17). The stress experienced by caregivers causes the release of corticosteroids and endorphins which reduce immune functioning. This makes caregivers more susceptible to infectious illnesses. It is important to note that one's perception of the stressor is important and may be a precipitating factor to immune depletion. Furthermore, being stressed can result in poor eating patterns, sleep disturbances and the ingestion of substances that may further impair immune functioning (Barlow & Durand, 1999). Therefore, the responsibilities of caregiving are stressful and may result in stress-related diseases, such as high blood pressure, duodenal ulcers and heart disease (Hartke & King, 2003). This illustrates the biological implications associated with caregiving that require consideration and are addressed via a biopsychosocial approach, hence the question in the interview from the present research that taps into the physical effects of caregiving (see appendix A).

Han & Haley (1999) found that few studies focused on reducing the pressures families are confronted with, and there is a need to consider the combined effect of education and support in assisting caregivers in their role. This is reiterated by the fact that they are often unprepared and overwhelmed by the demands and responsibilities that define the role of a caregiver.

Caregivers of individuals with cognitive impairments are in need of continuous support particularly on the challenges of behaviour management. Most caregivers are also uninformed of the costs of nonmedical care and options for coverage (Moscowitz, 2002). Studies have indicated that between 45% and 49% of patients and their caregivers are dissatisfied with the pre-discharge information received concerning stroke (O'Connell, Baker & Prosser, 2003). Additionally Low, Payne & Roderick (1999) found that caregivers' coping abilities are increased by stroke information. Family members have reported being less informed than patients (Van Veenendaal et al., 1996). Family members consider the major areas that lack information to include: sources of assistance, strategies for daily activities, and precautions to reduce the onset of another stroke (Van Veenendaal et al., 1996). In a study conducted in the United Kingdom on traumatic brain injury, the majority of the 200 families in the sample reported receiving inadequate information in the following areas: consequences of TBI, aftercare, referral sources and prognosis. An additional concern is limited contact with psychologists and neuropsychologists. This lack of information affected the ability for the caregivers to carry out their role (Bowen, Tennant, Neuman & Chamberlain, 2001). Recurrent strokes are more debilitating physically and financially than first strokes, and are thus a valid concern for patients and families (Denby & Harvey, 2003).

Additional concerns based on international research regarding caregivers emphasise the fact that modern families are geographically dispersed, female caregivers have joined the workforce, local communities are less concerned with individual needs, and caregiving spouses or children may have medical needs of their own (Moscowitz, 2002). Regardless of how devoted the caregiver may be, they are often consumed with career or marital responsibilities, and assuming this role may be at the expense of their career or even the sacrifice of a marriage; as this major task vastly alters the quality of one's life (Youngson, 1987). These factors play an integral part in the ability of the caregiver to meet the requirements accompanying their complex and demanding role. "Recognising caregivers as a rehabilitation resource and providing information to caregivers about how to assist stroke survivors with treatment would aid stroke survivors in the rehabilitation process and provide caregivers with an opportunity to participate in care" (O'Connell et al., 2003, p.27). The action of placing power in the hands of the caregiver may be a positive attribute for the caregiver, in terms of them feeling needed and fulfilling a vital role in the household.

According to Bakas and Burgener (2002) low self-esteem, high task difficulty, and high threat appraisal are predictors of emotional distress in caregivers. Lazarus' Transaction-based Theory of Stress and Coping (1966) proposed that antecedent personality and situational factors are primarily mediated by cognitive appraisal, and influence emotional and adaptation results in settings or events (Bakas & Burgener, 2002). According to this model, stress is a result of the transaction between an individual and their environment, rather than the event itself, and coping involves management of the stressful setting and not necessary mastery.

Effective coping is considered to involve the achievement of an activity without cost to anything of importance to the individual. Folkman and Lazarus (1985) stated that assessing coping traits may be a poor indicator of ways in which people actually cope in a situation. Alternatively, three criteria must be satisfied to evaluate coping as a process: coping must be examined within the context of a stressful encounter; what the person does as opposed to what they usually do; and there needs to be multiple assessments during the encounter to assess coping over time as the encounter unfolds.

Folkman (1984) identifies two major functions of coping, which is regulating emotions and distress and the management of the problem causing distress. These are described by Lazarus and Folkman (1984) as problem-focused coping and emotion-focused coping, both major response strategies used to cope with stressful experiences. Problem-focused coping strategies can be defined as efforts to alter an aspect of the environment or of self, and therefore resemble problem-solving tactics. On the other hand, emotion-focused coping strategies are geared toward reducing emotional distress, and include tactics such as avoiding, distancing, selective attention, blaming, wishful thinking, minimising, venting emotions, seeking social support, exercising, as well as meditating. Emotionally-focused coping is more commonly used when the situation is unchangeable, such as the incidence of stroke. Terry (1991) suggests that emotion-focused coping is related to poor adaptation to stress as it fails to confront the event, however, both strategies may occur simultaneously and compliment one another (Carver & Scheier, 1994). This model offers a framework to guide individuals who struggle to adjust to the challenges of stroke care, and the issues and concepts pertinent to this model are compared to research findings in chapter 5 of this research report.

Gender differences in response and approach to caregiving have revealed that men primarily focus on problem resolution, whereas, women focus on emotional resolution, which is closely related to sex role socialisation. Women are also more likely to express difficulties concerning their caregiving role (Hartke & King, 2003). Whether the findings of the present study support this premise will be discussed in chapter 5.

Certain personality characteristics predispose people to cope in certain ways when faced with adverse conditions and functional coping strategies are associated with personality qualities that are widely considered as beneficial (Carver, Scheier & Weintraub, 1989). Carver, Pozo, Harris, Noriega, Scheier, Robinson, Ketcham, Moffat & Clark (1993) state that there is an abundance of evidence that avoidance coping is positively correlated to concurrent distress, and that avoidance coping is a prospective predictor of distress when confronting a major stressor.

Common coping strategies employed by caregivers include: taking one day at a time, adopting a positive attitude, having a sense of humour, and indulging family support (O'Connell et al., 2003). Emotions can be more effectively dealt with by expressing feelings, rather than bottling them up, and work in the area of grief is a useful way for patients and their families to establish new and healthier patterns of living (Lyon, 2002). Repression of feelings can make the situation worse, as the caregiver needs to be reassured that these feelings are natural and reasonable to the context. Therefore an expression of feelings can prove to be highly therapeutic (Youngson, 1987). One needs to identify the main areas responsible for stress, and find ways to reduce their effect. Possible ways are taking assistance from family members and

friends to allow some independent time away from the patient, set priorities of responsibilities and let some duties of lesser importance go, engage in relaxation and recreational activities, and join a support group (Youngson, 1987). Problem-focused coping strategies are strongly correlated with an emphasis on the positive and seeking social support (Folkman & Lazarus, 1985). The data collection instrument enabled the researcher to take cognisance of the coping strategies employed by each participant and the impact thereof, as the open-ended nature of the questions allowed the participant scope to provide great detail of their family life. However, the focus of this research was on caregiver effects and family dynamics and therefore, the analysis centred on these themes as opposed to ways of coping.

The challenges associated with caregiving need to be explored, as patients place a significant financial and emotional strain on their families (Zillmer & Spiers, 2001), hence the aims of the present research which examined the interrelated nature the biological, psychological and social effects of stroke on the patient's caregiver and family, focusing on these issues through the social dimension. The present study provides a local, in-depth perspective into the effects of stroke on the family by investigating a South African sample, as existing literature depicts international findings which are difficult to extrapolate to the South African context.

The next section provides insight into some of the issues that needed to be considered when conducting the present study.

## 3.5 Family caregiving within the South African context

The family has been defined in numerous ways; according to Scherz, as cited in Beaver and Miller (1992), "most people who have written about the human family conceive of it as a group of people in interaction. Human beings are inseparably tied to the emotional and interactive bonds that emerge from their existence in the family. In fact, the basis of becoming a social being is thought to originate in the family". Reber (1995) states that family in the strictest sense refers to the fundamental kinship unit, in its nuclear form consisting of father, mother and offspring. However, in broader usage it may refer to the extended family operating as a recognised social unit, and including grandparents, cousins and so on. Sociologists and anthropologists have numerous classifications for various types of family units as they are represented in different cultures and societies. Therefore, cultural and structural variations may characterise various groups of families within a particular society (Becvar & Becvar, 1996). South African families vary in terms of their structure and are largely determined by their culture, for example non-westernised families could be defined as an extended family unit, whereas more acculturated or westernised families generally assume a more nuclear form. The White Paper for Social Welfare (1997) stipulates that families have been vastly affected by the social, economic and political policies of the past, and the inequitable distribution of resources, social changes, migration patterns, the growing subculture of violence, as well as the redefinition of the traditional roles of both genders.

Similarly, caregiving responsibilities are associated with multiple variables, including family structure, resources, and contemporary social policy. Caregiver burden derives not only from

the experiential aspects of living with illness in the family, but also from the caregiver's interactions and frustrations with the treatment system, including the welfare and legal system not to mention an indifferent society. However, the burden can be mitigated by the appropriate assistance of the treatment system and the community at large (Hatfield, 1987; cited in Lefley, 1996). Therefore, attitudes of the community and treatment received by health professionals can be sources of stress for caregivers (Lefley, 1996). The act of caring is expressed in interpersonal interaction and need not be restricted from one person to another, therefore, society as an entity has a role to play in care. A weakening factor is that care is devalued in society, and professional caregivers are generally the least powerful and obtain the lowest income in society. Additionally, literature reveals that the expression of care is culturally defined in South Africa (Muelenberg-Buskens, Shaw & Daniels, 1997).

The primary caregiver broadly refers to the individual who is first in line to provide care to the individual in need of assistance (Reber, 1995). Caregiving distress may be manifested in multiple ways, be it physiological and psychological, and is commonly a function of individual response styles as well as cultural norms. There are cultural differences in perceptions of burden, and the more the family perceives caregiving as part of their responsibility, the less likely they are to provide information on caregiving tasks and burden. However, caregiving burden may be considerably reduced depending on the resources and social support available (Lefley, 1996).

A study conducted in the United States has distinguished between individualistic cultures (typically western or modern) and group oriented cultures (typically non-western or

traditional). These cultural styles are relevant to the caregiving process. Traditional cultures generally contain an interpersonal moral code that stresses responsibility to the family, therefore, caregiving tasks are likely to be perceived as less burdensome (Miller, 1994; cited in Lefley, 1996). Conversely, non-western families may experience greater burden due to poorer economic circumstances, and may choose to make use of traditional methods and adaptive resources for coping, as western medical assistance may be out of their reach. Within the realities of the South African context this seems to be a relatively probable scenario, due to the financial strain experienced by many living in rural communities that are so greatly lacking in resources necessary to address the treatment of stroke patients and their families.

Insufficient funding of services and research along with negative expectations of recovery, affect the available resources for caregivers. Family composition and structure as well as size and density of household are important variables; these in turn are influenced by socio-economic status and cultural norms for living arrangements in the household. Loss of employment and other threats to the socio-economic health of the family, such as famine or political strife can pressure an already vulnerable family to breaking point. International and cross-cultural research suggests that family caregiving is affected by two factors: societal resources and cultural norms. Traditional cultures frequently coexist with low levels of industrial development and few alternatives to family caregiving (Lefley, 1996). In South Africa it is unlikely that provincial health departments will be able to accommodate the amount of extra resources required in specific underprivileged communities, there is thus no guarantee that desired level of funding for health care or equitable allocations will be made (Doherty & van den Heever, 1997). According to the South African Department of Health (Doherty & van

den Heever, 1997) senior doctors are rare species in rural hospitals, in cities there is one doctor to every 700 people, whilst in rural areas there is one doctor to every 10 000 to 30 000 people. This illustrates the extreme lack of resources available to address the basic requirements of people living in this country. One can only envision the strain families are under when having to care for a stroke patient under these adverse circumstances. Lack of medical assistance and financial strain may culminate in family members having to rely on the patient's disability grant as the only source of income for the family.

Indigenous South African beliefs and healing systems form an integral part of the culture of many South Africans. This may be due to a preferential understanding of the explanation, significance, diagnosis and treatment of illness provided by an indigenous healer because of a worldview based on African cosmology, or as a result of poor accessibility to and a sense of alienation from western health systems, particularly in rural areas. In South Africa, a large portion of the population who make use of indigenous healers, in the past, have had only limited access to even the most basic western primary health care resources. Additionally, this traditional approach reiterates the notion that health and illness are conceptualised around the belief that people do not exist in isolation but are dynamically enmeshed in a web of relationships and influences other people, spirits, and nature, the disturbance of which will result in affliction and harm (Werner, 1987). As a result of these differences a non-westernised family subscribing to indigenous South African beliefs will differ vastly in terms of their understanding of and resultant effect of stroke and caregiving, in comparison to a South African family living in an urban area, subscribing to western conceptualisations of the cause and implications of health and disability. An ethnographic assessment conducted in South

Africa indicated a plural healing approach to illness. Illness is understood as caused by biomedical problems (xilungu, white, western) as well as by social problems (xintu, African, traditional). Most conditions require two-pronged treatment. Stroke (xistroku) is perceived as a biomedical disease, but a form of bewitchment (xifulana) is caused by humans through dysfunctional social relations, and could manifest through weakness down one side. Therefore, xistroku can be treated by allopathic professionals; however, xifulana requires intervention from traditional healers and churches. The majority seek help from both practitioners and traditional healers, as traditional beliefs do not prevent the use of allopathic medicine. Multiple modalities are thus employed on the part of the patient. Physicians need to listen and negotiate with patients whilst understanding the diverse views of illness (The SASPI Project Team, 2003).

As suggested by Werner (1987), it is likely that stroke patients will live within the rural community and not expected to live independently from the family. Furthermore, Werner (1987) hypothesises that where poverty is extreme; disability is of little importance to the family in comparison to other more pressing needs such as food and shelter. Therefore, the perception of caregiving within South Africa is not universal but very specific to each family, dependent on variables such as socio-economic status, religious beliefs, and culture. Needs and problems of families are quite varied. One should view families through the lenses of their particular level of need in order to identify their strengths and weaknesses, whilst considering people and their environments within their historic and cultural contexts.

# CHAPTER 4: METHODOLOGY

## 4.1 Research Design

The research design of the present study was qualitative and cross-sectional in nature. Cross sectional research takes a slice of time and compares subjects on one or more variables simultaneously (Rosenthal & Rosnow, 1991). According to Mason (1996) qualitative research is 'interpretivist' in its orientation, whilst based on a philosophical stance that focuses on how the social world is interpreted and understood. Flexible data collection techniques that are sensitive to the social context are employed. This accommodates the social context of the participants and their experiences. Based on these ideals, a qualitative methodology was the appropriate design for purposes of the present study. Methods of analysis involved an emphasis on detail and a deep understanding of context and complexity. Although quantification was utilised to a small degree in order to elicit trends and patterns, statistical procedures were not central to this approach. The emphasis was on attaining rich, contextual data based on holistic forms of analysis; in line with the ideals of systems theory and the biopsychosocial perspective which enabled the aims of this study to be achieved.

This research study drew on a non-probability purposive sampling technique; therefore, the participants were selected according to certain criteria which served the purposes of the research, without randomisation. This sampling technique was suitable to the qualitative nature of the present study as its aim was to attain rich, in-depth data as opposed to attaining strong external validity (Henning, van Rensburg & Smit, 2004).

## 4.2 Research Questions

1. What are caregivers' perceptions of the biological, psychological and social effects of stroke on the family system?
2. What are caregivers' perceptions and experiences of the medical and psychological services available for stroke patients?

## 4.3 Sample

The present study involved a sample of 6 caregivers from the Neurovascular clinic at the Johannesburg General Hospital, who volunteered to partake in the study. Selection was based on the medical records of the stroke patient as well as the demographics of the family, pending a 12 month post-stroke adaptation period. This allowed the family and caregiver enough time to adjust and experience the biopsychosocial effects associated with stroke.

Inclusion criteria constituted: the caregiver being the spouse or child of the stroke patient, and the patient not being institutionalised, thus, enabling more data on caregiving to be attained. For the sample to be as demographically representative as possible, a translator was on call to be utilised in cases where the participant did not have conversational fluency in English. The translator was a psychology masters student at the University of the Witwatersrand fluent in various indigenous South African languages, and understood the confidentiality and ethical issues involved in this endeavour. However, the translator was never utilised as the researcher never encountered a point in the interview procedure where the participant failed to

comprehend the questions or struggled to express him or herself therefore, providing comprehensive responses to the questions asked.

Specifications were not adopted regarding gender and race thus enabling an ethnically diverse sample to emerge. As the Johannesburg General Hospital is a public, teaching institution, most patients came from poor socio-economic backgrounds, or alternatively had utilised their medical aid to its maximum and had to seek government assistance.

This study focused on the first three types of stroke mentioned in chapter one, namely: cerebral thrombosis, cerebral embolism, and haemorrhages; as they require greater post-stroke care, and thus, enabled the exploration of the challenges faced by the caregiver and family as a consequence of these conditions. These types of strokes were included due to the limited sample size, whilst additionally including various levels of dysfunction in stroke patients which resulted in specific experiences for the caregiver.

No one that was approached to participate in the study refused. However, the strict criteria excluded many individuals. It was challenging to source black caregivers as most black stroke patients were unaccompanied although their level of disability was similar to that of their white counterparts. Based on the selection criteria, the table on the following page illustrates the sample obtained in the present study and will be discussed in chapter 5 of this research report.

**Table 1: Demographic details of caregivers that partook in the study**

| *Age* | *Gender* | *Race* | *Number of children* | *Relation to stroke patient* | *Time of stroke* | *Type of stroke experienced by patient* |
|---|---|---|---|---|---|---|
| 49 | Male | Coloured | 2 | Husband | 13 yrs ago | Blood clot |
| 37 | Female | White | 2 | Daughter | 2 yrs ago | Blood clot |
| 56 | Female | White | 2 | Wife | 4 yrs ago | Blood clot |
| 58 | Male | White | 3 | Husband | 1.5 yrs ago | Aneurysm |
| 67 | Female | White | 3 | Wife | 3 yrs ago | Unknown |
| 16 | Female | Black | 0 | Daughter | 3 yrs ago | Unknown |

## 4.4 Procedure

Data collection involved the administration of a semi-structured interview consisting of open-ended questions (see appendix A). It was feasible to utilise an open-ended, semi-structured measurement in the field of assessing caregiving problems, as it "allows for greater breadth and depth of inquiry" (Hartke & King, 2002, p.31). The semi-structured interview enabled the probing into sensitive issues, whilst allowing flexibility on the part of the researcher, as the open-ended questions were 'funnel type' in nature, thereby starting with broad questions and moving to more specific, narrow questions as the interview progressed (Rosenthal & Rosnow, 1991). This amount of flexibility was imperative for this type of study as it provided the opportunity to explore issues relating to caregiving and the effects of stroke on the family working with interviewee responses, whereas a more structured interview may have failed to tap into issues that required further exploration.

A pilot study was carried out in order to assess the structure of the questions and to check for ambiguity. Revisions of the interview questions were made accordingly. This revision involved the elimination of one question that appeared to be a repetition of the previous question.

The length of the interview was set at a maximum of one hour in an attempt to avoid the process being long and tiresome as the participants generally had many chores to attend to. Care was taken to ensure the interviews were conducted in a quiet, private setting at the Neurovascular clinic. Therefore, participants did not have to make special arrangements at their expense. Furthermore, no incentive to participate in the study was offered. Due to the delay for their consultation with the neurologist, which is generally an hour or more as the clinic works on a 'first come first serve basis', all participants found it convenient to partake in the present study. The interviews were conducted by the researcher and all were audio-taped and transcribed verbatim.

## 4.5 Data Analysis

Analysis of the data took the form of thematic and content analysis, in order to identify themes and sub themes. This type of analysis enabled the classification of the open-ended material provided by the semi-structured interviews; with an emphasis on meaning rather than quantification (Rosenthal & Rosnow, 1991). The objective was to provide an accurate and coherent picture of caregivers; by describing the processes, mechanisms and relationships in their daily lives.

According to Rubin and Babbie (1989) content analysis is a way of transforming qualitative data into quantitative data and consists primarily of coding and tabulating the occurrences of certain forms of content that are being communicated. A further description of content analysis by Denzin & Lincoln (1994) states that it is a research tool used to determine the presence of certain words or concepts within texts or sets of texts. Researchers quantify and analyse the presence, meanings and relationships of such words and concepts, then make inferences about the messages within the texts, the writer, the audience and even the culture and time of which these are a part. Content analysis is a useful technique for describing the focus of an individual or group, it allows inferences to be made which can then be corroborated using other methods of data collection, it is useful for examining trends and patterns and provides an empirical basis for monitoring shifts in public opinion (Stemler, 2001). For these reasons it is often used as a means of analysing interviews and hence was used in the present study.

Content analysis extends beyond simple word counts. It is a technique, which is rich and meaningful in its reliance on coding and categorising of the data. Categories must be mutually exclusive and exhaustive (Stemler, 2001). Content analysis is essentially a coding operation, whereby communications are coded or classified according to some conceptual framework (Rubin and Babbie, 1989).

A system of quantification of manifest content (the obvious content) and latent content (the underlying meaning) was undertaken in the process of coding the data of this study. Themes with the same underlying meaning were coded together and the text was then analysed for relationships and associations among the themes (Titscher, Meyer, Wodak & Vetter, 2000).

The themes that emanated from the analysis were then compared to the assumptions of systems theory and the biopsychosocial approach as the questions were structured to tap into these frameworks. Due to existing literature on stroke, expected themes included: role changes, irritability of family members, guilt feelings, altered social life, financial problems, health problems, occupational problems, sexual problems, rejection or over-protectiveness of the spouse caused by ignorance of how to interact with the patient, and effects on children, as well as inadequate medical and psychological services (Van Veenendaal et al., 1996; Zillmer & Spiers, 2001; Malone, 1964; Fritz & Penn, 1992). Therefore, the researcher assessed whether these themes emerged, whilst being open to new themes.

In summary, the steps or phases of analysis followed in this research included:

1. Orientation to the data. This involved the reading of data in order to form an overview and understand the context.
2. Working the data. Here the coding of segments of meaning, categorising related codes into groups, and seeking relationships between categories to form thematic patterns, took place.
3. Final composition of the analysed data text. This involved the writing of the final themes of the set of data, whilst presenting a pattern of related themes (Henning, van Rensburg & Smit, 2004).

Content Analysis is therefore a powerful data reduction technique. Its major benefit is that it is a systematic and replicable technique for compressing many words or text into fewer content-based categories on explicit rules of coding. This method is unobtrusive and can

deal with large volumes of data (Stemler, 2001). It is limited in that it is time consuming, subject to increased error, often devoid of a theoretical base and is inherently reductive, particularly when dealing with complex texts (Denzin & Lincoln, 1994). Therefore, the researcher in the present study was aware of this and was vigilant in forming categories. Two fatal flaws that destroy the utility of content analysis include faulty definitions of categories and non-mutually exclusive and exhaustive categories (Stemler, 2001). However, this qualitative technique enabled the researcher to uncover the meaning and significance of social phenomena for people in their context, providing a rich representation of the research area whilst searching for commonalities and differences across cases. This approach was vital to the aim of this study as an in-depth investigation based on caregivers' perceptions and experiences of the implications of stroke was required (Ragin, 1994).

## 4.6 Ethical considerations

Ethical clearance was obtained by the Higher Degrees as well as the Ethics Committee of the University of the Witwatersrand. Furthermore, permission to conduct the present study in the Neurovascular Clinic was granted by the senior consultant neurologist. The senior psychologist of the Psychology Department at the Johannesburg General Hospital also agreed for participants to be referred to her for counselling if the need arose.

Specifications of the auspices of the study were clearly stated to the participants as well as the voluntary nature of their participation. They were informed of their right to withdraw at any

time. The participants were required to consent to partake in the study as well as to be audio-taped; therefore two consent forms (see appendix C and appendix D) were completed by the participants. Confidentiality was guaranteed by a system of coding which was employed to protect the identity of the participants, and the audiotapes were deleted after use.

# CHAPTER 5: RESULTS AND DISCUSSION

As mentioned in the previous chapter the sample consisted of 6 caregivers. Prior to commencing with the semi-structured interview (see appendix A), a few questions were asked in order to ensure that the participants fulfilled the inclusion criteria of the present study as well to establish the demographics of the sample. The inclusion criteria involved the caregiver being the spouse or child of the stroke patient and the patient having suffered a cerebral thrombosis, cerebral embolism, or haemorrhage no less than 12 months ago, whilst not being institutionalised. This period post-stroke enabled the effects of stroke to be experienced by the each member of the family system. The figure on the below depicts the ages of the participants.

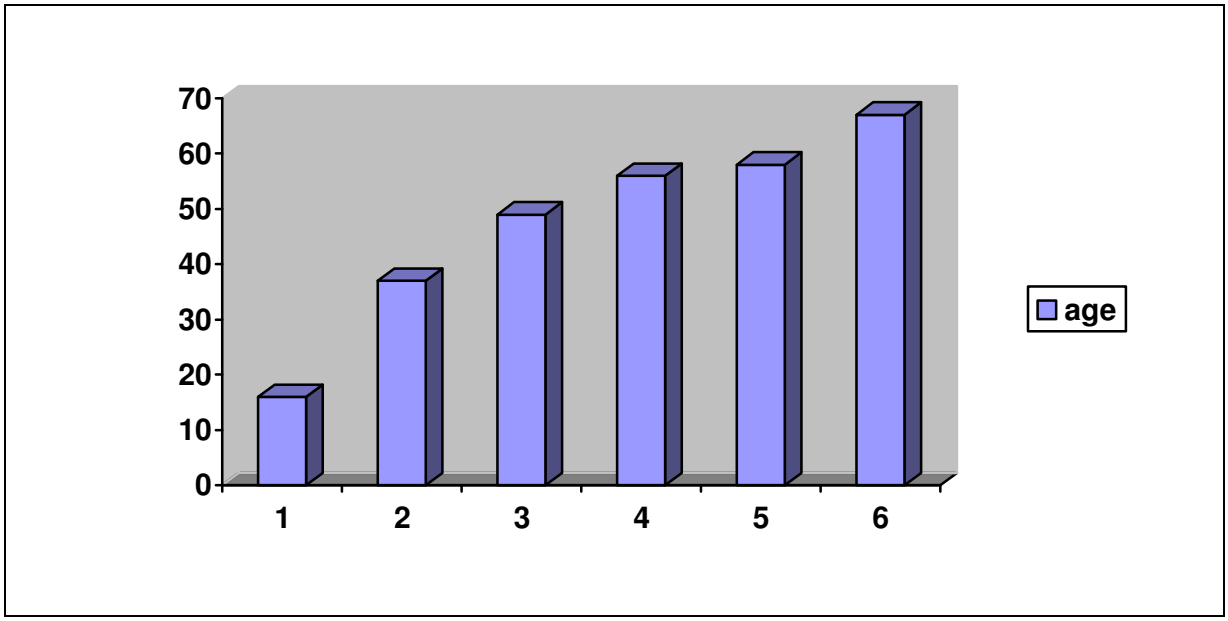


**Figure 1: Ages of the participants**

Most of the sample was in the middle to senior adult age bracket, apart from one participant who was 16 years old. The ages of the sample ranged from 16 to 67 thus covering a rather broad age spectrum with a skewed sample distribution. Due to the strict inclusion criteria resulting in a limited sample size, the researcher was forced to be less stringent on the ages of the participants.

The sample consisted of two males and four females, with both males being relatively close in age, 49 and 58 years respectively. There were three white participants, one black and one coloured participant. By including participants of diverse ethnicity, the researcher was able to identify important themes possibly relating to culture. Relation to the stroke patient included: four spouses and two children (both daughters) of the stroke patients. All but one of the participants had children of their own. The causes or types of stroke experienced by the patient included blood clots and an aneurysm, however, information concerning the stroke for two of the participants was not provided in the medical records and nor were the participants able to inform the researcher as to the cause or type of stroke suffered, illustrating poor communication between health professional and patient. This lack of information being passed on to the stroke patient and their caregiver by health professionals is an area of great concern and will be discussed in more detail a bit later. All the patients were disabled to some degree and required the help of the caregiver in order to carry out daily activities. This enabled the researcher to investigate the challenges associated with caregiving. See table 1 in chapter 5 for an illustration of these demographics. A noteworthy point regarding the ages of the stroke patients, was their lack of consistency in age i.e. not all of them were above the age of 50 as two of the stroke patients in the present study were in their thirties when they suffered a stroke,

although stroke is most common in the over 50 age bracket (Statistics South Africa, 2002). This finding reflects the extent to which stroke has increased across age and culture (The SASAPI Project team, 2004).

The questions of the interview used in the present study were formulated in consultation with the literature to tap into various issues of caregiving. Due to the semi-structured nature of the interview the results of the study will be discussed based on the responses of the participants for each question whilst identifying themes and sub themes. The transcriptions of these responses is included in appendix E, however, responses that were completely unrelated to caregiving were excluded from this research report, and hence were not included in appendix E.

The researcher found the male and female participants equally responsive and emotive. However, other research in this area found women more likely to express the difficulties associated with their caregiving role (Hartke & King, 2003). Perhaps the data collection environment and instrument used allowed all participants to feel comfortable to express emotion, the fact that the confidential nature of the study was emphasised may have been an additional factor that promoted open communication.

## 5.1 Question 1: Can you describe your family structure i.e. who lives in your home?

Question 1 deals with the structure of the family system, and this structure i.e. who live in the home, impacts on the caregivers' experiences as well as family dynamics.

All the participants lived with the stroke patient; however, with four of the six participants other family members also lived in the same house. These family members included the caregiver and stroke patient's children and their respective spouses. Therefore, the two participants that lived alone with the stroke patient did not receive the additional assistance and support the other caregivers may have experienced from family members. One of these caregivers was a black 16 year old daughter of a stroke patient who received no familial support at all. This is inconsistent with literature on the collectivist nature of non-western cultures (Lefley, 1996); however, one needs to bear in mind that this family system resides in central Johannesburg, an urban area. Furthermore, the qualitative design of this study limits the external validity of this finding due to the modest sample size and lack of population representation.

On the other hand, two of the four participants that lived with other family members reported difficulties concerning their living arrangements. These difficulties were based on the feelings of the stroke patients who found it challenging to adjust to these circumstances post-stroke, with the caregivers stating, "…he feels it is not his home, we are living with my daughter and her husband, they support us, and my husband struggles with that" and, "My wife wants us to move out but I am not able to financially, she feels that our sons don't understand her and she keeps saying she needs to get out of this environment". In both cases the couples lived on their own prior to the stroke and this could have impacted on these reactions. The emotional consequences of stroke such as emotional lability, anger, frustration, apathy and low self esteem (Zillmer & Spiers, 2001) had a substantial effect on the caregiver, illustrated by the difficulty of the stroke patient to become reintegrated within the family system. This increased

pressure on the caregiver. Based on systems theory, each family member needs to adjust to the altered situation post-stroke and restore the equilibrium of the system, which is a strenuous time for all involved, whilst coping styles may vary for each family member (Becvar & Becvar, 1996; Faison et al., 1999), which may be an additional stressor for the caregiver.

## 5.2 Question 2: How would you describe the relationships within your family system?

This question was geared to identify the family dynamics within the family system as well as determine ways of coping. There was a large overlap between the responses to question 2 and question 6 which addressed how relationships have changed since becoming a caregiver.

The relationships within the family system post-stroke according to the perception and experiences of the participants elicited a diverse range of responses from, "…explosive at times", "Negative…" to, "Very good" and "We are close". One participant felt that the stroke brought the family closer. Once again this was reported by the black participant, however, the other five participants considered the period post-stroke to be one of adjustment. One caregiver considered their long marriage to be a coping mechanism that pulled them through, stating, "… it's harder to work through when you're younger", yet another felt that age was a driving force as their whole lives were still ahead of them and the couple had young children, he also mentioned "…we get external help"; illustrating the importance of social support to increase coping. One caregiver mentioned that the family became less supportive over time after the stroke. A participant, who was the wife of the stroke patient, found that their relationship had changed following the stroke although his relationship with his children had not altered. She

mentioned that, “He is sometimes like a child, very childish and that irritates me” she also stated that, “He also cries a lot. He wasn’t like that before”. An additional theme that emerged from two participants included the strained relationship between the stroke patient and their children. This proved particularly challenging for the caregiver as they were forced to mediate between their spouse and their children, stating, “I’m stuck in the middle”, and “… my wife has become withdrawn since her stroke and feels that no-one likes her anymore. She says she feels ‘wooden’ so I go between my wife and sons”. This places an additional strain on the caregiver and may be a precipitating factor to pathology in this population.

These responses exhibit different ways of coping based on the unique circumstances of each family system with length of relationship and social support being factors that enhanced coping skills for caregivers. Noteworthy was that only one participant (the 16 year old, black caregiver) did not associate any adjustment post-stroke although that was a theme for the other five participants. Once again this has implications for the study in terms of using certain age groups and cultures.

With stroke being an unanticipated sudden event, preparation is not an option for the family system. Family roles redefined and therefore, it takes time to develop these parameters within the constraints of the stroke patient’s disability (Germain, 1984; Schlesinger, 1985). Based on the comments of the participants and correlating these responses to the length of time of stroke post-stroke, it was evident that the more time the family system had post-stroke, the better adapted they became, hence seeking social support depicting problem-focused coping strategies (Lazarus & Folkman, 1984).

### 5.3 Question 3: How would you describe your role as a caregiver?

The participants were asked to describe their role as a caregiver and three participants (half of the sample) felt that they were coping with it, stating, "Good, coping with it", "Its alright, I'm used to it now", and, "Its ok, I'm coping with it". These responses were categorised as positive, whilst the other three participants' responses involved detailed descriptions of the tasks they perform as caregivers, thus depicting more negative associations with the role of caregiving. These tasks included assisting the stroke patients with various activities, ensuring they receive their medication, and monitoring that they don't have another stroke or epileptic seizure. A theme that emerged quite strongly was the need to watch the stroke patient on a continual basis resulting in elevated levels of anxiety. This finding echoes results of international research conducted by Hartke and King (2002) that found anxiety to be an emotion an outcome of the caregiving process.

### 5.4 Question 4: How have you experienced caregiving physically?

Question 4 taps into the biological and physical ramifications of caregiving. Elevated levels of fatigue as a result of caregiving were expressed by four participants, with one participant stating that, "… I also get sick often. I have continuous lung infections from stress. I'm on antidepressants as well". Stress-related illnesses in caregivers due to immune depletion have been documented in previous studies (Hartke and King, 2003; Malone, 1964), along with sleep disturbance leading to fatigue (Van Veenendaal et al., 1996). It was interesting that the 16 year old participant only expressed difficulty in caregiving when asked this question, responding

with, "I sometimes get tired but I have to do it because she's my mother", which reflects that she performs her caregiving role out of a sense of duty. This supports the literature that stipulates that traditional cultures tend to perceive caregiving as less burdensome (Lefley, 1996; Werner, 1987). Her ability to identify with the more physical aspect of caregiving as opposed to the emotional dimension can be due to her immaturity. There were no obvious gender specific themes i.e. one male participant found caregiving physically challenging, whilst the other did not.

## 5.5 Question 5: How have you experienced caregiving emotionally?

The emotional or psychological implications were elicited by question 5. One participant went into great detail on how he reached burn-out two years after the stroke, "… I 'conked in'. I had reached burn-out and had a panic attack…If you don't have support you've had it". He brought up the financial strain associated with caregiving as well the importance of a support network. Another participant also referred to her support system, "When I get upset I call my daughter and she supports me". Role reversal was also highlighted as an issue that was difficult to adjust to, "In the past my wife was the strong one, so our roles had reversed". The continuous worrying or anxiety about the possibility of the patient experiencing another stroke was a pressing issue for one participant with her saying, "I just worry about him all the time…"; whilst the psychological impact of the financial strain they are under was mentioned by two caregivers. Depression and feeling "annoyed" was also expressed by one participant. Therefore, the fundamental psychological themes associated with caregiving included depression and anxiety. The primary precipitating factor to these emotions was financial strain.

Establishing social support was considered the most important approach to increase coping based on the responses of two participants. These themes are consistent with previous studies by Malone (1964), Van Veenendaal et al., (1996) and Hartke and King (2002) whereby family members of stroke patients were reported to struggle with emotional distress and financial strain. Furthermore, the importance of support was emphasised be the participants in the present study, which is also consistent with literature on coping with stroke as these studies found that education and support assisted caregivers in their role (O'Connell et al., 2003; Youngson, 1987).

### 5.6 Question 6: How have your relationships (with the stroke patient or family members) changed since becoming a caregiver? Can you give me an example of this?

The participants were asked how their relationships had changed following the stroke. The changes expressed by one participant centred on the disability of his wife and the effect it has had on the lives of their children. This couple received counselling on a regular basis from their minister, whilst the caregiver received psychotherapy after his breakdown to increase levels of coping. According to Hartke & King (2003) mediators such as care skills, education regarding disability, and a support system, can positively influence coping and distress. These variables therefore act as buffers. Based on the participants' opinions, this premise was validated in the present study as the participants with more established support networks and education on stroke had superior levels of coping.

Malone (1964) stipulated the effect on children as a consequence of stroke. The sub theme of children appeared to emanate only in this case where the children of the stroke patient were young and still living at home, whereas negative ramifications for elder independent children even in cases where the stroke patient was residing with them, was not expressed. The challenges faced by the young children of the stroke patient in the present study included being teased about their parent's disability at school, having a great deal of responsibility from a young age, resulting in increased coping skills due to their circumstances. However, two other participants mentioned that the stroke patient has a poor relationship with his/her children, placing the caregiver in a compromising position. This intensifies the challenges of caregiving. One participant stated that the change in their marital relationship affects her, but this has no ramifications for their children as they are not living with them and have families of their own. Therefore, family relationships were more strained when family members resided in the same house. Two participants felt that their relationships had not changed post-stroke, incongruent with previous literature on stroke as well as the reported experiences of the other four participants in the present study.

## 5.7 Question 7: How has your social and/or occupational (work) life been affected?

This question tapped into the social and occupational effects of stroke. Considering occupation, work related themes included having to take time off to take the stroke patient to medical appointments and feeling anxious at work, "When I did work I used to worry about him all the time". One participant had to resign in order to take care of the stroke patient as he required the care of a nurse and that was too costly for them. Noteworthy, is the recurring theme in the

present study of the financial strain placed on the family of stroke patients, which was mentioned in other studies conducted abroad (Van Veenendaal et al., 1996; Malone, 1964; Hartke & King, 2003).

Social implications were also experienced, with one participant highlighting the effect this has had on the social life of their children, "The kids used to love camping, but now they have to go with friends, my wife can't do that. They also love going to the movies but my wife is sensitive to light so we don't go anymore. One of us has to stay with my wife at all times-we take turns. I miss the spontaneity; the stroke restricts our lives…" Three participants stated that their social lives had been affected, whilst two participants explained the impact the stroke had on their occupation. The noteworthy comment by one caregiver concerning the effect on the entire family system, "…stroke restricts our lives", ties in with Hartke and King's (2002) study which highlighted the sense of burden experienced by caregivers of stroke patients (although the term burden was not used by the participant, but rather 'restricts'), along with the association between caregiver distress and type and severity of stroke impairments (Bakas & Burgener, 2002). Predictably, the greater the disability the more demanding the role of the caregiver and the more adaptation required on the part of the family.

## 5.8 Question 8: Describe a typical day as a caregiver

When asked to describe their typical day as a caregiver the researcher was able to identify the extent of chores involved in the caregiving process for these caregivers which in turn impacted

on their lives resulting in biological, psychological and social ramifications. Tasks associated with caregiving for the participants included:

- Monitoring that the patient does not have a seizure, another stroke, or place themselves or others in danger, for example, forgetting to switch the stove off.
- Bath and dress the patient.
- Ensure the patient receives their medication.
- Assist the stroke patient with physical activities, such as climbing stairs.
- Attend to household chores.
- Taking care of children.

The 16 year daughter of the patient has to cook, clean the house and bath the patient whilst still attending school; this depicts the extent of her responsibilities. One caregiver stated, “I’m always there for him; he is never there for me”, whilst another verbalised, “He goes to bed at 7 o’clock and I sit and watch TV alone”. These negative connotations indicated an additional sub theme of loneliness, with both participants having similar family systems i.e. mature children that have families of their own, so their spouse was their only companion. Both participants had positive relationships with their children, but there seemed to be an underlying loneliness based on these responses which Hartke and King (2002) stipulated as an emotional reaction for caregivers of stroke patients. This has a strong link with the psychosocial and neurological ramifications of stroke for the stroke patient, which in turn affects the caregiver as well as the entire family system as each member of the system is influencing and being influenced simultaneously (Becvar & Becvar, 1996). The experiences of the family system were exacerbated by the disability and behaviour of the stroke patient.

## 5.9 Question 9: What do you consider as the most challenging task as a caregiver?

The most challenging task of caregiving was specific to every caregiver with responses including time, "Time. You don't have a life of your own- no time to yourself… having to take on all the responsibilities of child rearing…"; role reversal particularly with caregivers who were children of the stroke patient; mediating between the patient and others due to their poor communication skills; the emotional side of the patient i.e. their labile emotional state; financial difficulties; transport issues i.e. attending medical appointments as there is no family support, "I have to miss school to come, my family doesn't help us, we catch a taxi here". These responses comprised the most prominent themes associated with the negative aspects of caregiving. Only one participant mentioned communication to be the most stressful factor to cope with, although this was a primary stressor in a previous study by Van Veenendaal et al. (1996).

## 5.10 Question 10: Describe the services you received pre and post discharge (psychological as well as medical)

Question 10 enabled the researcher to identify problems with the health care services received by the participants, exploring the effects of this system on their family systems, thus truly working from a systems perspective and viewing the participants' situations in context.

The health services received from the public sector were relatively positively perceived by five of the six participants, whereas all participants that had been treated in private hospitals prior to

their admission to a government hospital were appalled by the service they received in the private sector. The only complaints concerning the government hospital included the lack of continuity as different registrars work at the clinic, a lack of general information regarding stroke, 'There is no after care advice… I've learnt how to handle it", and its disorganised nature. Two of the caregivers were referred for psychological help by the consulting neurologist; however, the other four participants did not receive any information on the psychological impact of stroke on the patient or the family. Four of the participants stated that no educational information on stroke prevention was provided. The importance of education in terms of preventing another stroke and providing support has been emphasised greatly in the literature (Han & Haley, 1999; Moscowitz, 2002; O'Connell et al., 2003; Van Veenendaal et al., 1996) and is thus an issue that urgently needs to be addressed by the medical community. Furthermore, family therapy aims to improve interaction between family members, thus, facilitating coping (Fritz & Penn, 1992) and therefore, should be discussed by the consulting physician as an option for the family.

Treatment should focus on reducing caregiver depression and family dysfunction, as well as providing the family with education on stroke care (Van Veenendaal et al., 1996). Hopefulness has been shown to be a driving force regarding a family's coping with the effects of mental illness, and health professionals need to respect and acknowledge the importance of hope in the process of grief and acceptance (Bland & Darlington, 2002). However, the first step for a caregiver to take in order to prevent stress and perpetuate coping, is to be aware of the perceived demands involved and the resources available to meet these demands (Lyon, 2002).

## 5.11 Question 11: What recommendations do you have for the health services in South Africa i.e. how can they be improved?

When asked how the services provided to stroke patients and their families could be improved, recommendations for improvement suggested by the participants included: providing pamphlets and brochures on post-stroke care, to run the stroke clinic in the morning as patients tire quickly and often have to return the following day as the medicine dispensary closes or alternatively dispense from the clinic, and the treatment of the patients needs to improve, "…shouldn't treat the patient like a number". An additional concern was the lack of social support for younger stroke patients outside the hospital as many stroke organisations accommodate older patients as stroke is relatively age related and if young, "… felt out of place". This illustrated a more proactive coping style as this was the only family that looked into support groups available for stroke patients and their families. This participant was provided with the contact details of a South African organisation that specialises in support groups of various natures.

In summary, the present study explored the biological, psychological and social dimensions of caregiving addressed by question 4, 5, and 7 respectively; whilst acknowledging the interaction within each family system as well as the influence health care systems adds to their experiences, hence question 10 and 11. Therefore, effects of stroke were experienced by the caregiver on many levels i.e. biologically or physically, psychologically or emotionally, as well as socially. Prominent themes concerning the difficulties of caring for a stroke patient included: role changes particularly in cases where the caregiver was the child of the stroke

patient; relationship disruption in the family system as the period post-stroke was perceived by most (5) as one of adjustment, irritability due to the patient's behaviour post-stroke, restricting as a great deal of social constraint was experienced relating to the stroke patient's degree of disability, exhausting due to the tasks involved in the caregiving role, anxiety and depression was an outcome for some participants, occupational implications, and financial problems. An additional point was that the participants found that the younger the children the greater the effect of stroke on them. However, as previously mentioned, the more support in the form of psychotherapy and practical and emotional assistance from extended family and friends, the greater the ability to cope. The importance of social support was emphasised, with two of the six participants admitted to not being able to cope alone and obtained professional help, which increased their coping abilities. The only discrepancy to the above themes was that one participant did not perceive the caregiving role to be of any challenge, but rather one that she performs out of a sense of duty, and this could be due to her cultural ideals. The other five participants found aspects of caregiving to be difficult, having biological, psychological and social ramifications for them and their respective family systems.

As the family system is embedded in the context of other systems from health services to their community and society, issues concerning the health care system were investigated. These services were perceived positively by five of the six participants, however, when asked if they had received any education post-stroke, four participants considered this to be a crucial problem. Inadequate post-stroke information was congruent with other studies in this area that emphasise the need to improve this issue thus enhancing caregivers' coping abilities, whilst assisting the stroke patient in terms of stroke prevention.

# CHAPTER 6: CONCLUSION

With restrictions on resources in the South African health care systems, patients are discharged to the long-term care of their families and therefore, these caregivers need to be equipped with the appropriate information and support to fulfil the challenging and demanding role of caregiving. The present study identified various areas of caregiving that had biopsychosocial consequences for caregivers and their respective families. Furthermore, results indicated a lack of post-stroke information from medical practitioners. Based on these findings, there is a need to develop and implement educational materials that address caregiver needs. Caregivers and families need to be empowered in order to assume more effective caregiving roles. This requires the assistance of health care professionals so that families of stroke patients increase their capacities for illness management and coping skills.

Systems theory and the biopsychosocial approach provided a beneficial framework as the entire context of the caregivers' experiences were explored. This theoretical perspective allowed for the various dimensions of the caregiving process to be investigated, thus providing comprehensive results that considered interaction across multiple levels.

The primary limitation of this study was its sampling technique, as the sample was selected based on a non-probability sampling method. This implies that conclusions of this study cannot be generalised to the entire stroke population, family members, and services rendered as the participants may not be representative of the general population. The limited sample size threatens the reliability of these results. However, having stated these limitations, the

methodology employed by the present study aimed to provide an in-depth view into the effects of stroke on the family system, looking at these effects on many levels, whilst acknowledging the influence the South African context adds to these experiences. Therefore, although the methodology may be accused of being non-scientific in its approach, it enabled the researcher to uncover the meaning and significance of stroke for caregivers and their family systems. Thus this study achieved the objectives of providing an invaluable contribution to the field of psychology and neurology, beneficial to practitioners of various disciplines. The applicability of this research is broad, as it may be utilised in other illness areas such as HIV/AIDS and cancer. Additionally, it may be used as a pilot study for the formulation of an inventory that assesses the mental health of families affected by stroke.

Suggestions for further research in this area include a stroke incidence study geared towards understanding the causes of stroke as well as the types and subtypes, providing insight into the risk factors of stroke, specific to the South African context. Interventions to improve family functioning post-stroke should be researched, in order to ensure that the suitable issues are being addressed. A more quantitative study based on the present study's results would also be very beneficial to the sub-specialties, family and health psychology.

With the insufficient health care systems in South Africa due to lack of infrastructure, staff and morale, as well as other competing demands, such as HIV/AIDS, one can elicit the challenge of generating adequate resources to address the increasing prevalence of stroke. The impact of stroke has been highlighted by the present study, and it is thus imperative that stroke is addressed on a national level and steps be taken in a prophylactic manner i.e. through

education and increased awareness of risk factors for stroke. The prevention and treatment of stroke need to be integrated into the health system, as opposed to being dealt with independently, and resources need to be improved to mitigate the impact of stroke. Active community skills development and participation in health-related issues need to be primary concerns. Working at a grass-roots level is recommended in a multicultural society like South Africa in order to adequately address health care issues. Therefore, addressing specific needs and not merely providing a top-down approach to stroke intervention that ignores the local illness taxonomy and requirements of the community, but instead working collaboratively with communities.

# REFERENCES

Akamatsu, T. J., Stephens, M. A. P., Hobfoll, S. E. & Crowler, J. H. (1992). *Family Health Psychology.* USA: Hemisphere Publishing Corporation.

Alonso, Y. (2004). The biopsychosocial model in medical research: the evolution of the health concept over the last two decades. *Patient Education and Counselling, 53*(2), 239-244.

Bakas, T. & Burgener, S.C. (2002). Predictors of emotional distress, general health, and caregiving outcomes in family caregivers of stroke survivors. *Topics in stroke rehabilitation, 9* (1), 34-45.

Barlow, D. H. & Durand, V. M. (1999). *Abnormal Psychology* (2nd Ed.). USA: Brooks/Cole Publishing Company.

Basso, A., Capitani, E. & Moraschini, S. (1982). Sex differences in recovery from aphasia. *Cortex, 18*, 469-475.

Beaver, M. L. & Miller, D. A. (1992). *Clinical social work practice with the elderly: Primary, secondary and tertiary interventions* (2nd Ed.). California: Wadsworth Publishing Company.

Becvar, D. S. & Becvar, R. J. (1996). *Family therapy- a systemic integration* (3rd Ed.). Boston: Allyn & Bacon.

Bland, R. & Darlington, Y. (2002). The nature and sources of hope: Perspectives of family caregivers of people with serious mental illness. *Perspectives in Psychiatric care, 38*(2), 61-68.

Bowen, A., Tennant, A., Neuman, V. & Chamberlain, A. M. (2001). Neuropsychological rehabilitation for traumatic brain injury: Do cares benefit? *Brain injury, 15*(1), 29-38.

Brown, G. G., Spicer, K. B. & Malik, G. (1991). Neurobehavioural correlates of anteriorvenous malformations and cerebral aneurysms. In R. A. Bornstein. (Eds.). *Neurobehavioural aspects of cerebrovascular disease*. New York: Oxford University Press.

Brown, G. G., Spicer, K. B. & Robertson, W. M. (1989). Neuropsychological signs of lateralised arteriovenous malformations: Comparisons with ischemic stroke. *The Clinical Neuropsychologist, 3*, 340-352.

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V.M., Scheier, M. F., Robinson, D. S., Ketcham, A. S., Moffat, F. L. & Clark, K. C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology, 65*(2), 375-390.

Carver, C. S. & Scheier, M. F. (1994). Situational coping and coping dispositions in a stressful transaction. *Journal of Personality and Social Psychology, 66*(1), 184-195.

Carver, C. S., Scheier, M. F. & Weintrub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 54*, 267-283.

Ceruti, M. (1994). *Constraints and possibilities. The evolution of knowledge and knowledge of evolution.* New York: Gordon & Breach.

Chodosh, E. H., Foulkes, M. A., & Kase C. S. (1988). Silent stroke in the NINCDS Stroke Data Bank. *Neurology, 38*, 1674-1679.

Costa, L. & Spreen, O. (Eds.) (1985). *Studies in neuropsychology*. New York: Oxford University Press.

Crosson, B. A. (1992). *Subcortical functions in language and memory*. New York: Guilford Press.

Denby, F. & Harvey, R.L. (2003). An educational intervention for stroke rehabilitation patients and their families: Healthy living after stroke. *Topics in stroke rehabilitation, 9*(4), 34-45.

Denzin, N. K. & Lincoln, Y. S. (1994). *Handbook of Qualitative Research*. USA: Sage Publications.

Doherty, J & van den Heever, A. (1997). Is there a role for a health formula in the new provincial budget system? *Health Systems Trust update, 22*.

Edmans, J. A. & Lincoln, N. B. (1989). The frequency of perceptual deficits after stroke. *British Journal of Occupational Therapy, 52*, 266-270.

Eisenburg, D., Kessler, R., Foster, C., Norlock, F., Calkins, D. & Delbanco, T. (1993). Unconventional medicine in the United States: Prevalence, costs, and patterns of use. *New England Journal of Medicine, 328*, 246-252.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196,* 129-136.

Engel, G. (1980). The clinical application of the biopsychosocial model. *American Journal of Psychology, 137*, 535-544.

Engel, G. (1982). The biopsychosocial model. *New England Journal of Medicine, 306*, 802-805.

Ellis-Hill, C.S. & Horn, S. (2000). Change in identity and self-concept: A new theoretical approach to recovery following a stroke. *Clinical Rehabilitation, 14*, 279-287.

Faison, K.J., Faria, S.H. & Frank, D. (1999). Caregivers of chronically ill elderly: Perceived burden. *Journal of Community Health Nursing, 16*(4), 215-233.

Feigin, V. L., Lawes, C. M. M., Bennet, D. A. & Anderson, C. S. (2003). Stroke epidemiology: a review of population-based studies of incidence, prevalence, and case-fatality in the late 20th century. *Lancet Neurology, 2*, 43-53.

Folkman, S. (1984). Personality control and stress and coping processes: A theoretical analysis. *Journal of Personality and Social Psychology, 46*(4), 839-852.

Folkman, S. & Lazarus, R. S. (1985). If it changes it must be a process: A study of emotions and coping during three stages of a college examination. *Journal of Personality and Social Psychology, 48*(1), 150-170.

Fritz, V & Penn, C. (1992). *Stroke: Caring and Coping*. Johannesburg: Witwatersrand University Press.

Germain, C. (1984). *Social Work Practice in Health Care: An ecological perspective*. New York: Free Press. In V. Fritz & C. Penn. (Eds.). (1992). *Stroke: Caring and Coping*.

Han, B. & Haley, W. E. (1999). Family caregiving for patients with stroke: review and analysis. *Stroke, 30,* 1478-1485.

Hartke, R. J. & King, R. B. (2002). Analysis of problem types and difficulty among older stroke caregivers. *Topics in stroke rehabilitation, 9*(1), 16-33.

Hartke, R. J. & King, R. B. (2003). Telephone group intervention for older stroke caregivers. *Topics in stroke rehabilitation, 9*(4), 65-81.

Henning, E., van Rensburg, W. & Smit, B. (2004). *Finding your way in qualitative research.* Pretoria: Van Schaik Publishers.

Kase, C. S. & Mohr, J. P. (1986). General features of intracerebral haemorrhage. In H. J. M. Bennet et al. (Eds). *Stroke. Pathophysiology diagnosis and management.* New York: Churchill-Livingston.

Kerns, R. D., & Turk, D. C. (1985). *Behavioural medicine and the family: Historical perspectives and future directions*. In D. C. Turk & R. D. Kerns. (Eds.). Health, illness, and families: A life-span perspective. New York: Wiley-Interscience.

King, R. B., Shade-Zeldow, Y., Carlson, C. E., Feldman, J. L. & Philip, M. (2002). Adaptation to stroke: A longitudinal study of depressive symptoms, physical health, and coping process. *Topics in stroke rehabilitation, 9*(1), 46-66.

Knopman, D. S., Selnes, O. A., Niccum, N. & Rubens, A. B. (1984). Recovery of naming in aphasia: Relationship to fluency, comprehension and CT findings. *Neurology, 34*, 1461-1470.

Lai, S., Studenski, S., Duncan, P. W. & Perera, S. (2002). Persisting consequences of stroke measured by the stroke impact scale. *Stroke, 33*, 1840-1844.

Lazarus, R. (1966). Psychological stress and the coping process. New York: McGraw-Hill. In Lyon, B. L. (2002). Psychological stress and coping: Framework for poststroke psychosocial care. *Topics in stroke rehabilitation, 9*(1), 1-15.

Lazarus, R. & Folkman, S. (1984). Psychological stress and the coping process. New York: Springer. In Lyon, B. L. (2002). Psychological stress and coping: Framework for poststroke psychosocial care. *Topics in stroke rehabilitation, 9*(1), 1-15.

Lefley, H. P. (1996). *Family Caregiving in Mental Illness*. United States: Sage Publications, Inc.

Lezak, M. D. (1995). *Neuropsychological Assessment* (3rd Ed.). Oxford: Oxford University Press.

Lishman, W. A. (1987). *Organic psychiatry* (2nd Ed.). Oxford: Blackwell.

Low, J. T. S., Payne, S., Roderick, P. (1999). The impact of stroke on informal carers: A literature review. *Social Science and medicine, 49*, 711-725. In O' Connell, B., Baker, L. & Prosser, A. (2003). The educational needs of caregivers of stroke survivors in acute and community settings. *Journal of Neuroscience, 35*(1). 21-28.

Lyon, B. L. (2002). Psychological stress and coping: Framework for poststroke psychosocial care. *Topics in stroke rehabilitation, 9*(1), 1-15.

Magni, G. & Schifano, F. (1984). Psychological distress after stroke. *Journal of Neurology, Neurosurgery, and Psychiatry, 47,* 567-571.

Malone, R. L. (1964). Expressed attitudes of families of aphasics. *Journal of Speech and Hearing Disorders,* 146-151.

Mason, J. (1996). *Qualitative Researching.* London: Sage Publications.

Meyer, W. F., Moore, C. & Viljoen, H. G. (1997). *Personology: From individual to ecosystem.* Johannesburg: Heinemann.

Mochan, A., Modi, G., & Modi, M.M. (2003). Stroke in black South African HIV-positive patients: A prospective analysis. *Stroke, 34*, 5-10.

Moscowitz, B. (2002). Bridging to family and community support for older adults and the domain management model. *Topics in stroke rehabilitation, 9*(3), 75-86.

Muelenberg-Buskens, I., Shaw, S. F. V. & Daniels, K. (1997). Caring qualities of health care workers. *Health Systems Trust update, 22*.

Murdoch, G. E. (1990). *Acquired speech and language disorders: A neuroanatomical and functional neurological approach*. New York: Chapman and Hall.

Nelson, L. D., Cicchetti, D. & Satz, P. (1993). Emotional sequelae of stroke. *Neuropsychology, 7,* 553-560.

O' Connell, B., Baker, L. & Prosser, A. (2003). The educational needs of caregivers of stroke survivors in acute and community settings. *Journal of Neuroscience, 35*(1), 21-28.

Ogden, J. A., Mee, E. W. & Henning, M. (1993). A prospective study of impairment of cognition and memory and recovery after subarachnoid haemorrhage. *Neurosurgery, 33,* 1-15.

Pardeck, J. T. & Yuen, F. Y. (2001). Family health: An emerging paradigm for social workers. *Journal of Health and Social Policy, 13*(3), 59-74.

Powers, W. J. (1990). Stroke. In Pearlman, A. L. & Collins, R. C. (Eds.), *Neurobiology of disease*. New York: Oxford University Press.

Prigatano, G. P. (1999). *Principles of Neuropsychological Rehabilitation*. Oxford: Oxford University Press.

Ragin, C. C. (1994). *Constructing Social Research. The unity and diversity of method*. USA: Pine Forge Press.

Reber, A. S. (1995). *Dictionary of Psychology* (2nd Ed.). England: Clays Ltd, St Ives plc.

Rosenthal, R. & Rosnow, R. L. (1991). *Essentials of Behavioural Research: Methods and Data Analysis.* (2nd Ed.). New York: McGraw-Hill.

Rubin, A., and Babbie, E. (1989*). Research Methods in Social Work* (3rd Ed.). Australia: Wadsworth.

SASPI Project Team. (2003). Southern Africa stroke prevention initiative report.

SASPI Project Team. (2004). Prevalence of Stroke in Rural South Africa. Results from the Southern Africa Stroke Prevention Initiative (SASPI) Agincourt Field Site. *Stroke, 35*, 627-632.

Schlesinger, E. (1985). Health care social work practice: Concepts and strategies. St. Louis: Mosby College Publishing. In V. Fritz & C. Penn. (Eds.). (1992). *Stroke: Caring and Coping*. Johannesburg: Witwatersrand University Press.

Signer, S., Cummings, J. L. & Benson. D. F. (1989). Delusions and mood disorders in patients with chronic aphasia*. Journal of Neuropsychiatry, 1*, 40-45.

Starkstein, S. E. & Robinson, R. G. (1992). Neuropsychiatric aspects of cerebral vascular disorders. In *Textbook of neuropsychiatry* (2nd Ed.). Washington: American Psychiatric Press.

Statistics South Africa. (2002). Causes of death in South Africa 1997-2001: Advance release of recorded causes of death. *Statistics South Africa*: Pretoria.

Stemler, S. (2001). An Overview of Content Analysis. *Practical Assessment, Research and Evaluation, 7*(17).

Terry, D. J. (1991). Coping resources and situational appraisals as predictors of coping behaviour. *Personality and Individual Differences, 12*(10), 1031-1047.

The White Paper for Social Welfare (1997). In Mokone, J. M. (1999). The role played by the family as a support system for the elderly and the challenges of caregiving. *Social work, 35*(2), 133-137.

Titscher, S., Meyer, M., Wodak, R. & Vetter, E. (2000). *Methods of Text and Discourse Analysis.* London: Sage.

Van Veenendaal, H., Grinspun. D. R. & Adriannse, H. P. (1996). Educational needs of stroke survivors and their family members, as perceived by themselves and by health professionals. *Patient Education and Counselling, 28*, 265-276.

Von Bertalanffy, L. (1968). *General systems theory.* New York: Braziller.

Wade, S. L., Taylor, G., Drotar, D., Stancin, T. & Yeates, K. O. (1997). Impact on the family. In E. D. Bigler, E. Clark, & J. E. Farmer. (Eds.). *Traumatic Brain Injury: Diagnosis, Assessment and Intervention.* Texas: Proed.

Walsh, K. W. (1985). *Understanding brain damage.* Edinburgh: Churchill-Livingston.

Walsh, K & Darby, D. (1999). *Neuropsychology: A clinical approach* (4th Ed.). Edinburgh: Churchill-Livingstone.

Walton, J. N. (1994). *Brain's diseases of the nervous system* (10th Ed.). Oxford: Oxford University Press.

Weiss, P. (1977). The system of nature and nature of systems: Empirical holism and practical reductionism harmonised. In K. E. Schaeffer, H. Hensel, & R. Brody. (1977). *Towards a man-centred medical science.* New York: Futura Publishing Company.

Werner, D. (1987). *Disabled Village Children: A guide for community health workers, rehabilitation workers and families.* USA: The Heperian Foundation.

Whyte, E. M. & Mulsant, B. H. (2002). Post stroke depression: epidemiology, pathophysiology, and biological treatment. *Biological Psychiatry, 52*(3), 253-264.

Youngson, R. M. (1987). *Stroke! A self-help manual for stroke sufferers and their relatives.* United States: A David and Charles Health Book.

Zillmer, E. A. & Spiers, M. V. (2001). *Principles of neuropsychology.* USA: Wadsworth/ Thomson Learning.

# APPENDIX A

**Semi-structured interview questions**

1. Can you describe your family structure i.e. who lives in your home?
2. How would you describe the relationships within your family system?
3. How would you describe your role as a caregiver?
4. How have you experienced caregiving physically?
5. How have you experienced caregiving emotionally?
6. How have your relationships (with the stroke patient or family members) changed since becoming a caregiver? Can you give me an example of this?
7. How has your social and/or occupational (work) life been affected?
8. Describe a typical day as a caregiver.
9. What do you consider as the most challenging task as a caregiver?
10. Describe the services you have received pre and post discharge (psychological as well as medical).
11. What recommendations do you have for the health services in South Africa i.e. how could they be improved?

# APPENDIX B

**Subject information sheet**

Hello,

My name is Mary Felemengas and I am a psychology masters' student at the University of the Witwatersrand. I am inviting you to participate in a research project on the effect that stroke has on the family.

*Why are we doing this?*

The research aims to provide a descriptive account of the difficulties and changes that result from stroke, concerning the patient's family system, and more specifically their primary caregiver. The research explores the challenges that the South African context adds to these experiences.

*What do we expect from you?*

You will be asked to: complete an audio-taped interview conducted by myself. This interview will take approximately 60 minutes to complete. All information disclosed by you will remain confidential. Your participation in this study is entirely voluntary and you may withdraw your participation, or refuse to answer questions I may ask, at any time.

*Why should I participate in this study?*

The knowledge accumulated through the interviews will be beneficial and significant to other caregivers as well as families affected by stroke. It may also highlight particular gaps within the South African medical and psychological system that require attention and development.

This study may awaken a range of emotions and therefore contact numbers of a counsellor shall be provided to you if the need arises.

If you are happy to take part in the study, please read and sign the attached consent forms.

Thank you,

Mary Felemengas

# APPENDIX C

**Consent form**

Dear Participant,

I am inviting you to participate in this study if you are the caregiver of a stroke patient who lives with you, and you are his or her spouse or child. Should you consent to participate, you will be asked to do the following:

- Complete an interview conducted by myself.
- Complete a consent form agreeing to have the interview audio-taped.

This interview will take approximately 60 minutes to complete. All information disclosed by you will remain confidential. Your participation in this study is entirely voluntary and you may withdraw your participation, or refuse to answer questions I may ask, at any time. If you agree to participate, please complete and sign this form.

Thank you for your time,

Mary Felemengas

I, _____ do/do not consent to participate in the research study to be conducted by Mary Felemengas.

Date: _____

# APPENDIX D

**Consent form for being audio-taped**

The interview for the study requires audio-taping in order to ensure that vital information is not lost during the research process.

I, _____ do/do not consent to having the interview conducted by Mary Felemengas being audio-taped.

Date: _____

# APPENDIX E

## Transcriptions

### *Question 1*

**Subject 1:** Husband (caregiver), wife (stroke patient), and two children.

**Subject 2:** Mother, father (stroke patient), husband, wife (caregiver), and two children.

**Subject 3:** Husband (stroke patient), wife (caregiver), daughter and son-in-law. "We live in their granny flat".

**Subject 4:** Husband (caregiver), wife (stroke patient), and three sons.

**Subject 5:** Husband (stroke patient) and wife (caregiver). "We have three daughters but they are all married and don't live with us anymore".

**Subject 6:** Mother (stroke patient) and daughter (caregiver).

### *Question 2*

**Subject 1:** "Positive, intimate and close. We have always been close. But we get external help from friends and family. The fact that my wife was only 31 years old when she had the stroke meant that we still had our whole lives ahead of us, we had to cope".

**Subject 2:** "Fine but can be 'explosive' at times, but my father interacts well with his grandchildren".

**Subject 3: "**Negative, my husband has not adapted well, he feels it is not his home, we are living with my daughter and her husband, they support us, and my husband struggles with that. I'm stuck in the middle".

**Subject 4:** "Look our long marriage has pulled us through because it's been difficult, it's harder to work through when you're younger. My wife wants us to move out but I am not able to financially, she feels that our sons don't understand her and keeps saying she needs to get out of this environment. My sons are also becoming less supportive now, I think they are getting sick and tired of dealing with my wife's emotional side. But my wife has become withdrawn since her stroke and feels that no-one likes her anymore. She says she feels 'wooden' so I go between my wife and sons".

**Subject 5:** "Very good. Things did change after the stroke. He is sometimes like a child, very childish and that irritates me. He also cries a lot. He wasn't like that before".

**Subject 6:** "We are very close, it's always been that way. The stroke brought us even closer".

***Question 3***

**Subject 1:** "She needed a lot of care initially, she couldn't even go to the toilet by herself, even now I have to help her with the stairs etc. She is paralysed in her left arm, but at least she doesn't need a wheelchair anymore. Only six years after the stroke was she able to drive, previously I always had to be with her. Now we have an understanding, I do all the running around and she helps the kids with their homework, although her short-term memory is 'shot'. She is not able to get a job; people find her unemployable because of her disability. This puts more pressure on me".

**Subject 2:** "I see to it that he takes his medication and always check that he doesn't have another epileptic fit or another stroke".

**Subject 3:** "Good. Coping with it".

**Subject 4:** "I have to watch her continuously. I have to make sure that she doesn't get into a panic about anything or forget the stove on. She needs to be reminded without upsetting her".

**Subject 5:** "Its alright, I'm used to it now".

**Subject 6:** "Its ok, I'm coping with it".

***Question 4***

**Subject 1:** "For two years I never slept through the night, and then I reached breaking point".

**Subject 2:** "It's tiring especially when my father is sick"

**Subject 3:** "I get very tired and I also get sick often. I have continuous lung infections from stress. I'm on antidepressants as well".

**Subject 4:** "It hasn't affected me physically".

**Subject 5:** "Not really".

**Subject 6:** "I sometimes get tired but I have to do it because she's my mother".

***Question 5***

**Subject 1:** "Two years after the stroke I 'conked in', I had reached burn-out and had a panic attack. In the past my wife was the strong one, so our roles have reversed. I reached my boiling point. So I started going for counselling and we moved to an area where we have support so not all the responsibilities rest on me. If you don't have support, you've had it. I previously had two maids to help me, but that was financially killing me. Now my wife doesn't rely on me as much, the people from our church take her out sometimes".

**Subject 2:** "I just worry about him all the time, has he taken his medication, is he going to have another stroke?".

**Subject 3:** "I get depressed. It's difficult to cope with my husband; he has changed since the stroke. We also have financial problems, our daughter and her husband support us, but its hard. We lost my husband's disability grant because no one told us we have to apply for it every year".

**Subject 4:** "I get annoyed with the situation, and I show it (which is bad) but I'm a temperamental person".

**Subject 5:** "When I get upset I call my daughter and she supports me".

**Subject 6:** "It's not difficult at all".

***Question 6***

**Subject 1:** "The children experienced a lot of trauma, they were teased at school because of their mother's disability. The youngest still slips occasionally, when she feels insecure. You know, they had a lot of responsibility from a young age. The children's coping skills have 'rocketed' because of the stroke, they've had to deal with a disabled mother. They had to grow up fast; I was always busy so they taught themselves from a young age. I still speak to my minister when I feel I need that support. We had to live as normal as possible. But, if places didn't have handicap facilities, we just wouldn't go, things like that".

**Subject 2:** "No".

**Subject 3:** "They have changed. He doesn't get on with his children. He is a hard person, he was always like that, but it got worse after the stroke. My relationship with my children is wonderful, it hasn't changed at all. But I'm stuck in the middle".

**Subject 4:** "Our sons want us to retire and they will help us financially, they are exceptionally dynamic people, especially the eldest, he controls the family".

**Subject 5:** "He has changed and that affects me, my children have their own lives so it doesn't affect them much".

**Subject 6:** "We are closer".

***Question 7***

**Subject 1:** "I worked with great difficulty, as I said for two years I never slept through the night between my wife and kids. I also had to take time off to take my wife to the clinic. It's changed their whole life. The kids used to love camping, but they have to go with friends, my wife can't do that. They also love going to movies but my wife is sensitive to light so we don't go anymore. One of us has to stay with my wife at all times- we take turns. I miss the spontaneity, the stroke restricts our lives. We used to go away often before the stroke, which has changed now; we really have to plan before we do things. The children adapted well, the youngest was only four months old when her mother had a stroke".

**Subject 2:** "He used to have a nurse but it was too expensive, now I look after him myself, so I no longer work. When I did work I used to worry about him all the time anyway".

**Subject 3:** "I don't work, I'm retired and my daughter and her husband support us, they don't mind".

**Subject 4:** "Our social life revolves around our children. We go out with them and their friends, but my wife prefers staying at home. My occupational life has not been affected".

**Subject 5:** "I have no social life".

**Subject 6:** "I go out on weekends with my friends".

***Question 8***

**Subject 1:** "Well someone is always with my wife, I take the kids to school, pick them up, she does their homework, I check she takes her medicine, and help her with stuff, because her left arm is paralysed".

**Subject 2:** "I see to it that my father receives his meds in the morning before work and after work that he is fed and takes his meds again. I also keep checking him, that he doesn't have another epileptic fit or another stroke".

**Subject 3:** "Make sure that I am always there for him, I check on him all the time. I'm always there for him but he is never there for me".

**Subject 4:** "Keep an eye on her, give her the medication she is meant to take".

**Subject 5:** "Bath him, cook, and give him his medication. I also help my children with their chores as well. He goes to bed at 7 o'clock and then I sit and watch TV alone".

**Subject 6:** "I go to school and then after school, I cook, clean the house, give my mom her medicine and bath her before I go to bed, I do homework after I bath her".

***Question 9***

**Subject 1:** "Time. You don't have a life of your own- no time to yourself. I had to take on all the responsibilities of child rearing, which is why I had to go for counselling. My wife completing depends on me. We were only married for 5 years when she had the stroke".

**Subject 2:** "Being the responsible adult, my father always looked after me and now it is vice versa. My mother is still alive but she is also sick, so I actually look after both of them".

**Subject 3:** "When my husband is in hospital, even when he comes here to the clinic I have to mediate between him and the doctors and nurses, so I have to be there all the time. He doesn't get on with anyone".

**Subject 4:** "Handling the emotional side of my wife, her depression, and mood swings".

**Subject 5:** "The financial problems, the medical aid ran out".

**Subject 6:** "To take her to her doctors' appointments, like coming to the clinic. I have to miss school to come, my family doesn't help us, and we catch a taxi here".

***Question 10***

**Subject 1:** "I attended a seminar held by the Stroke Society (a friend told me about it) and if I didn't have that at that particular time, I don't think I would have been able to cope at all. It taught us about what causes stroke, what to expect and what to do. We first went to a private clinic, but the service there was really bad (they don't have time to explain anything), and then we started coming to the clinic, it hasn't been bad here. But there is no continuity; you see a different doctor each time you come. My wife says she would rather die than go back to a private clinic; they don't want to listen to you at all. We were given much better service at the Gen, we received information on how to prevent another stroke but we were not told about where to go for psychological help. I went on my own, but we are coping as a couple".

**Subject 2:** "The clinic is tiring for my father, and the kids scream and that annoys him, but otherwise we are given excellent service. It's a bit disorganised until you get to see the doctor. I've read about stroke on my own, but the doctor explained what we must do".

**Subject 3:** "I'm very happy with the service, I was referred for counselling but we were not told how to prevent another stroke or what to expect".

**Subject 4:** "My wife was first misdiagnosed at the private clinic, and we went to several hospitals between Cape Town and Johannesburg. We wasted so much money on scans that we didn't need, so doctors need to investigate more. The problem is that there is no after care advice. Apart from the advice, I can't complain. You know my business crashed and that is how we ended up here, but the treatment has been fantastic. We were never told how to handle it; I've learnt how to handle it".

**Subject 5:** "Not so good. Its very disorganised, the clinic is mixed and noisy. We weren't given any advice after the stroke".

**Subject 6:** "They treat my mom ok, but we were not given any information".

***Question 11***

**Subject 1:** "They shouldn't treat the patient like a number, they have feelings and the doctors need to be sensitive to this. They should have more for younger stroke patients, my wife went to the Stroke Aid Society, but she felt out of place".

**Subject 2:** "No, not really".

**Subject 3:** "The medical queues are a problem that they need to sort out".

**Subject 4:** "Patients and their families need to investigate and get the support you need. They should give us brochures or pamphlets on stroke".

**Subject 5:** "You only get to see the doctor late and by then the medical dispensary has closed so you have to come again the next day. It would be better to run the clinic in the morning or dispense from the clinic".

**Subject 6:** "They need to treat patients better".