UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

THE EXPERIENCES OF PATIENTS AND CAREGIVERS FOLLOWING A STROKE

by

TSELENG MARTHA MAKGANYE

11298767

Mini-dissertation

submitted in partial fulfilment of the requirement for the degree

Master of Social Work (Health Care)

MSW (Health Care)

in the

Department of Social Work and Criminology

Faculty of Humanities

Supervisor: Dr CL Carbonatto

December 2015

© University of Pretoria

UNIVERSITY OF PRETORIA

FACULTY OF HUMANITIES

RESEARCH ETHICS COMMITTEE

DECLARATION

Full names of student: Tseleng Martha Makganye

Student number: 11298767

Topic of research report: The experiences of patients and caregivers following a stroke

1. I understand what plagiarism is and am aware of the University's policy in this regard.

2. I declare that this mini-dissertation is my own original work. Where other people's work has been used (either from a printed source, the Internet, or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.

3. I have not used work previously produced by another student or any other person to hand in as my own.

4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

SIGNATURE

DATE ……

© University of Pretoria

ACKNOWLEDGEMENTS

I give my heartfelt gratitude to the stroke patients and their caregivers for participating in this study. Your strength through the pain and your willingness to share your journey and experiences is an inspiration. Without you, this project could not have succeeded. You are loved and appreciated.

Glory to Almighty God for providing me with strength when I wanted to give up and for His unconditional love.

Special thanks to Richard Montsho and Mr Gidion Tebid, who gave me valuable input.

I also appreciate the patience and encouragement that my husband and children showed during this period. Thank you for your understanding and support during this time when I could not be as present as I would have liked. Tshepang, Reneilwe and Otshepeng, you are the pillars of my life.

Thanks to my gracious parents, Mr Peter and Mrs Magdeline Mmebe who taught me the true values in life and the importance of education.

My friends, Georgina, Joy, Paulina, Mantsho and Seipone, your encouragement is greatly appreciated. My colleagues and Mr Silwimba, I acknowledge and appreciate your support.

Lastly, I gratefully acknowledge the support and professional guidance of my supervisor Dr Charlene Carbonatto.

To all of you, thank you.

© University of Pretoria

Title: The experiences of stroke patients and caregivers following a stroke

Candidate: Tseleng Martha Makganye

Supervisor: Dr Charlene Carbonatto

Degree: Master of Social Work Degree in Health Care

Department: Social Work and Criminology

ABSTRACT

Stroke is emerging as the second leading cause of disability after HIV, and is a source of burden on the patient, relatives, friends, as well as consuming a great deal of health resources in South Africa (Kengne & Anderson, 2006:181). The onset of a stroke results in enduring changes in the lives of patients and caregivers, hence the objectives of this study constitute an investigation into the physical, psychological, social, religious and economic experiences of patients and caregivers following a stroke. In order to uncover changes experienced, an ecological perspective was used to explore a range of intertwining physical, social, emotional and economic problems. A collective case study design was used to gain a holistic understanding of how stroke patients and caregivers experience the aftermath of stroke. This study explored and investigated this matter in detail through the administration of semi structured interviews with five stroke patients and five caregivers. The sample size varied from what the researcher targeted; variation depended on saturation. The data was analysed qualitatively by thematic analysis.

The study revealed that a stroke is a condition characterised by a sudden onset, and that its symptoms were not previously known to the participants. Findings exposed that patients and caregivers experience multi-faceted and profound physical, social, emotional, financial, and spiritual changes. Patients experience physical consequences, such as decreased mobility and communication problems. Physical disability consequently compromises patients' functioning. The majority revealed that stroke caused them to be dependent as they could not resume their pre-stroke activities such as self-care, house work and going to work. Stroke furthermore caused patients to be emotionally distressed and to have to deal with a significant period of pain, confusion, hopelessness and depression

© University of Pretoria

before acceptance. The study also revealed social consequences of stroke, which include disruptions to family relationships, sexual problems and inadequate support structures available. It became evident in this study that the suffering following a stroke is not limited to that experienced by the victims, as caregivers also experience burdens such as physical and mental strain. Spirituality acts as a source of support for both the patients and the caregivers. Lastly, patients and caregivers did not receive adequate information and support from the health system during the acute phase.

Recommendations from this study include provision of comprehensive stroke education for both the community and healthcare workers; establishment of protocol-driven multidisciplinary care within the hospitals and in the clinics; integration of continuity of care between hospitals and the clinics; provision of continued guidance, information and support to patients and their families; and lastly, delivery of holistic care, which entails a combination of physical therapy, psychosocial support, as well as economic and social resources. Research that could conclusively unravel the relationship between the patient's mental state and the caregiver's mental state is also recommended.

Key terms:

Stroke, experiences, caregivers, patients

© University of Pretoria

TABLE OF CONTENTS

DECLARATION ..... **i**
ACKNOWLEDGEMENTS ..... **ii**
ABSTRACT ..... **iii**
LIST OF TABLES ..... **ix**
LIST OF FIGURES ..... **x**
1. CHAPTER ONE: GENERAL INTRODUCTION **1**
1.1 Introduction 1
1.2 Problem statement and rationale 3
1.3 Goals and objectives 5
1.3.1 Goal of the study 5
1.3.2 Objectives of the study 5
1.4 Research methodology 5
1.5 Limitations of the study 6
1.6 Presentation of the research report 6
2. CHAPTER TWO: LITERATURE REVIEW **8**
2.1 Introduction 8
2.2 Theoretical framework: Ecosystems perspective 8
2.2.1 Evolution and development 9
2.2.2 Key ecological concepts 10
2.2.3 The ecological perspective as a context in understanding stroke 12
2.2.3.1 Macrosystems 13
2.2.3.2 The ExoSystems 15
2.2.3.3 MesoSystems 15
2.2.3.4 Microsystems 17
2.3 Prevalence of stroke 18
2.4 Description and definition of stroke syndromes 20
2.4.1 Stroke 20
2.4.2 Transient Ischemic Attack (TIA) 20
2.5 Causes of stroke 20
2.6 Risk factors 21
2.7 Symptoms of stroke 22
2.8 Diagnosis of stroke 22
2.8.1 Physical examination 22
2.8.2 Laboratory tests 23
2.9 Means of prevention and treatment of stroke 24
2.9.1 Prevention of stroke 24
2.9.2 Drug treatment 24
2.9.3 Surgical treatment 25
2.9.4 Rehabilitation 25
2.10 Holistic effects of stroke on the patient 26
2.10.1 Physical and medical aspects 26
2.10.2 Emotional reactions 28
2.10.3 Social aspects 31
2.10.4 Economic aspects 33
2.10.5 Religious, spiritual and cultural aspects 33
2.11 Holistic effects of a stroke on the family and the primary caregiver 34

© University of Pretoria

2.12 Social work intervention with stroke patients and their caregivers from an ecological perspective 37
2.12.1 Social work intervention 37
2.12.1.1 Intervention during the phases of a stroke 37
2.13 Summary 39
3. CHAPTER THREE: RESEARCH METHODOLOGY, EMPIRICAL STUDY AND RESEARCH FINDINGS 41
3.1 Introduction 41
3.2 Research approach 41
3.3 Type of research 41
3.4 Research design 42
3.5 Research methods 42
3.5.1 Study population and sampling 42
3.5.1.1 Study population 42
3.5.2 Data collection 44
3.5.3 Data analysis 46
3.5.3.1 Planning for recording data 46
3.5.3.2 Data collection and preliminary analysis 46
3.5.3.3 Managing data 46
3.5.3.4 Reading and writing memos 47
3.5.3.5 Generating categories, themes and patterns 47
3.5.3.6 Testing the emergent understanding 47
3.5.3.7 Interpreting and developing topologies 47
3.5.3.8 Presenting data 48
3.5.3.9 Trustworthiness 48
3.6 Pilot study 49
3.7 Ethical considerations 49
3.7.1 Avoidance of harm 49
3.7.2 Informed consent 50
3.7.3 Deception of subjects 50
3.7.4 Violation of privacy/anonymity/confidentiality 51
3.7.5 Action and competence of the researcher 51
3.7.6 Debriefing of subjects 51
3.7.7 Publications of findings 52
3.8 Empirical findings of the study 52
3.8.1 Biographic profile of participants 52
3.8.1.1 Age 53
3.8.1.2 Gender 54
3.8.1.3 Marital status 55
3.8.1.4 Employment 56
3.8.1.5 Relation of caregiver to stroke patient 57
3.8.1.6 Time since onset of stroke 57
3.8.1.7 Diseases before stroke 58
3.8.2 Profile of research participants 58
3.8.3 Themes and sub-themes 59
3.8.3.1 Theme 1: Stroke onset 61
3.8.3.1.1 Sub-theme 1.1: Warning signs 61
3.8.3.1.2 Sub-theme 1.2: Seeking medical help 63
3.8.3.1.3 Sub-theme 1.3: Treatment received 64
3.8.3.1.4 Sub-theme 1.4: Understanding of stroke diagnosis 66
3.8.3.2 Theme 2: Physical consequences 70
3.8.3.2.1 Sub theme 2.1: Neurological impairments 70

© University of Pretoria

3.8.3.2.2 Sub-theme 2.2: Functional abilities 72
3.8.3.3 Theme 3: Spiritual, religious and cultural aspects 75
3.8.3.4 Theme 4: Financial consequences 77
3.8.3.4.1 Sub theme 4.1: Returning to work 77
3.8.3.4.2 Sub theme 4.2: Added financial costs 78
3.8.3.5 Theme 5: Emotional consequences 80
3.8.3.5.1 Sub theme 5.1: Feelings during the acute phase 80
3.8.3.5.2 Sub theme 5.2: Feelings during the chronic phase 82
3.8.3.5.3 Sub theme 5.3: Patient as a person 83
3.8.3.5.4 Sub theme 5.4: Emotional reaction of caregivers 85
3.8.3.6 Theme 6: Social consequences 86
3.8.3.6.1 Sub-theme 6.1: Social activities 86
3.8.3.6.2 Sub-theme 6.2: Sources of support 88
3.8.3.7 Theme 7: Patient's greatest loss 98
3.8.3.8 Theme 8: Caregiving burden 100
3.8.3.8.1 Sub-theme 8.1: Day-to-day tasks 101
3.8.3.8.2 Sub-theme 8.2: Health problems 102
3.8.3.8.3 Sub-theme 8.3: Aspect of distress for caregivers 103
3.8.3.9 Theme 9: Coping strategies 104
3.8.3.10 Theme 10: Recommendations 105
3.8.3.10.1 Sub-theme 10.1: Recommendations to stroke patients 105
3.8.3.10.2 Sub-theme 10.2: Recommendations to caregivers 106
3.8.3.10.3 Sub-theme 10.3: Recommendations for service providers 107
3.8.4 Summary 109

4. CHAPTER FOUR: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS 110

4.1 Introduction 110
4.2 Summary 110
4.2.1 Goal and objectives of the study 110
4.3 Key findings, conclusions and recommendations 112
4.3.1 Biographical details of the patients and caregivers 112
4.3.1.1 Key findings and conclusions: 112
4.3.1.2 Recommendations: 113
4.3.2 Theme 1: Onset of stroke 113
4.3.2.1 Key findings and conclusions: 113
4.3.2.2 Recommendations: 115
4.3.3 Theme 2: Physical changes 115
4.3.3.1 Key findings and conclusions: 115
4.3.3.2 Recommendations 116
4.3.4 Theme 3: Spiritual consequences 116
4.3.4.1 Key findings and conclusions 116
4.3.4.2 Recommendations 117
4.3.5 Theme 4: Economic consequences 117
4.3.5.1 Key findings and conclusions 117
4.3.5.2 Recommendations 118
4.3.6 Theme 5: Emotional consequences 118
4.3.6.1 Key findings and conclusions 118
4.3.6.2 Recommendations 119
4.3.7 Theme 6: Social consequences 119
4.3.7.1 Key findings and conclusions 119
4.3.7.2 Recommendations 120
4.3.8 Theme 7: Greatest losses 121
4.3.8.1 Key findings and conclusions: 121

© University of Pretoria

4.3.8.2 Recommendations: 121
4.3.9 Theme 8: Caregiver burden 122
4.3.9.1 Key findings and conclusions 122
4.3.9.2 Recommendations 122
4.3.10 Theme 9: Coping strategies 122
4.3.10.1 Key finding and conclusion 122
4.3.10.2 Recommendations 123
4.3.11 Theme 10: Recommendations 123
4.3.11.1 Key findings and conclusions 123
4.3.11.2 Recommendations for practice 124
5. REFERENCES 125
6. APPENDICES 133
6.1 Appendix A: Ethics Approval 133
6.2 Appendix B: Informed Consent Form - Caregivers 134
6.3 Appendix C: Interview Schedules 137
6.4 Appendix D: Clearance Certificate 139

© University of Pretoria

LIST OF TABLES

Table 3.1: Identifying details of participants (patients and caregivers) 533

Table 3.2: Profile of research participants 588

Table 3.3: Themes and sub-themes 599

© University of Pretoria

LIST OF FIGURES

Figure 3.1: Age of patients and caregivers (N=10) 544

Figure 3.2: Gender of participants (N=10) 555

Figure 3.3: Marital status of participants (N=10) 555

Figure 3.4: Employment status of patients and caregivers (N=10) 566

Figure 3.5: Relation to stroke patient (N=10) 577

Figure 3.6: Time since onset of stroke (N=10) 588

© University of Pretoria

1. CHAPTER ONE: GENERAL INTRODUCTION

1.1 Introduction

The sudden event of a stroke can lead to changes that have long-term consequences in everyday life, both for the person who has experienced stroke and for the caregiver (Ekstam, Tham & Borrel, 2011:49). A stroke is "a condition in which part of the brain is damaged, usually suddenly, either as a result of a blood vessel being blocked by a clot or due to a haemorrhage from a brain artery" (Steyn, 2007:2). In addition to the cerebral vascular accident, there may be other problems such as physical, emotional, family, marital, vocational, economic, as well as social challenges to contend with in the aftermath of stroke (Ross & Deverrel, 2010:157).

It is the second leading cause of death and disability worldwide, with 15 million strokes occurring annually. Of these, five million people die and another five million are left permanently disabled, placing an immense burden on the family and the community (Flanagan, Zaretsky & Moroz, 2011:549).

To estimate the burden of strokes in sub-Saharan Africa (SSA), several door-to-door community surveys were undertaken and the results broadly indicate an increasing incidence of strokes. Community surveys undertaken in Togo, Tanzania and South Africa suggest the prevalence of strokes to be between 200 and 300 per 100 000. More worrisome is the high prevalence of people living with stroke-related disability (200 per 100 000 population). These figures suggest a potential 400% increase in the burden of strokes over at least the last two decades (Kengne & Anderson, 2006:182).

The above statistics confirm that strokes are a health reality which puts strain on the health system, considering the prevalence rate in the United States of America, SSA and South Africa (SA). The National Clinical Stroke Guideline of 2008, as cited in Edmans (2010:177), acknowledges that two thirds of people who have a stroke will need some type of support and it will not be provided by healthcare workers, but by a mixture of family members and carers. It is unfortunate that this area of support has been neglected by practitioners and researchers. The above studies focussed on prevalence of stroke; however, the effects of stroke on housing, money, social life and general attitude towards life

© University of Pretoria

have been neglected by South African researchers (SASPI, 2004:627-632). In an attempt to address the above gap, this study was undertaken from the ecological approach which includes the aftermath of stroke on both the patient and the caregiver.

In terms of the researcher's experience, stroke-related problems are fast becoming a large proportion of the rehabilitation programme. Thus, this study explores and describes the experiences of stroke patients and their caregivers in order to gain a better understanding. It is important to highlight that the lack of recent research related to experiences of stroke patients and caregivers was also confirmed by the Assistant Director of the rehabilitation programme in the Tshwane district, Mr Silwimba (2013).

As the caregivers play a pivotal role in the rehabilitation of people who have had a stroke, this study explores the aftermath of stroke from the perspective of the patient and caregivers, rather than that of the service providers. It is culture-sensitive and relevant to the South African context. The current study was conducted with patients who experienced irreversible or major strokes and their caregivers in Soshanguve sub-district, which is in the north of the Tshwane district.

For the purpose of this study, the following key concepts are clarified:

- **Stroke**

It is a "heterogeneous condition consisting of haemorrhagic and ischemic attacks. Strokes are defined as minor/reversible and major/irreversible. Minor strokes include transient attacks which last less than 24 hours, whereas a major stroke is any cerebral vascular event resulting in permanent disability" (Bartels, 2011:2). For the purpose of this study, stroke is a brain attack, resulting from a blockage or ruptured blood vessels, in which the individual presents with different impairments. Minor or reversible strokes are not included in this study.

- **Experiences**

Experience "is seen as a product of social conditions or of systems of belief or practical contact with an observation or events. It is commonly used in a variety of overlapping ways that involve appeals to lived realities and dead certainties" (Williams, 1983 in Benett, Grossberg & Morris, 2005:123). For the purpose of this

© University of Pretoria

study, experience refers to physical, emotional, social, economic and religious aspects that are encountered by patients and caregivers due to stroke.

- **Patient**

A patient is “a person who is suffering from a disease, injury, an abnormal state of mind and is engaged in related medical treatment” (*Stedman’s Medical Dictionary*, 2012:1259). For the purpose of this study, a patient refers to a person who has some form of disability due to stroke and who receives treatment in a clinic or care at home.

- **Caregiver**

Caregiver is “any person, including a family member, who provides care or assistance to one who is ill” (*Stedman’s Medical Dictionary*, 2012:282). For the purpose of this study a caregiver will be anyone residing with and taking care of a stroke patient.

1.2 Problem statement and rationale

Stroke is a public health problem which affects low, middle and high income countries. It is a sudden, life-changing event with lifelong implications, including chronic disability and increased need for medical, social and caregiver support. This disease of the brain is common throughout the world, rendering it one of the greatest dangers to health, particularly in older populations (Eisenberg & Rashbaum, 2011:564). It is estimated that approximately 800 000 people in the USA experience stroke and the majority of them survive these encounters due to advanced treatment (American Heart Association, 2010). This implies that a number of people living with the aftermath of stroke have increased rates of disability.

Evidence indicates that case fatality rates for strokes in sub-Saharan Africa can be higher than in industrialised societies (Kengne & Anderson, 2006:180). This can be related to limited health care facilities and uncontrolled risk factors such as hypertension. The South African Stroke Prevention Initiative Study (SASPI, 2004:627-632) assessed the prevalence of stroke in the Agincourt demographic surveillance site in Mpumalanga. Stroke was about half as common in rural South Africa as in the typical high-income population. This study indicated that there

© University of Pretoria

were far more disabled stroke survivors in rural South Africa than in Tanzania, and about the same number as in New Zealand. It also acknowledged that stroke prevalence in urban areas is probably higher than in rural areas because people are exposed to more lifestyle risk factors.

Connor and Bryer (2005:200,201) have indicated the prevalence of people requiring help with activities of daily living as being higher in South Africa than in high-income countries and this places significant additional burden on the family and health services. They further highlighted that little is known about the socio-economic impact of stroke in South Africa and hence pleaded for new studies to focus on the causes of stroke and the true stroke burden and outcome. This will help practitioners to develop appropriate intervention strategies; thus the need for this study.

The above mentioned studies have hinted at a needed shift from only focussing on the patient to also investigating the aftermaths of stroke holistically. Little is known about how patients and caregivers feel about the care and support they receive, about how they want to be helped, about what information they require, about which problems distress them most and about how they view the main effects of stroke in their lives. This current study aimed to address this gap by exploring the aftermath of stroke on both the patient and the caregiver. The researcher was interested in finding the answer to the question, '**What are the experiences of patients and caregivers following a stroke?'** This question guided the researcher to find destination and guidance; hence it forms the foundation of this study (Kumar, 2005:44).

The motivation for this study results from a lack of recent research related to the experiences of stroke patients and their caregivers within the South African context. The researcher became aware of this lack of recent literature during a preliminary literature investigation. The researcher, in her experience as a social worker doing community-based rehabilitation, realised a need for updated research in this field. This current study endeavoured to heighten the knowledge of social workers with regard to stroke, and to provide a better understanding of the experiences of stroke patients and their caregivers. It also provides guidelines for social work intervention with these stroke patients and their caregivers.

© University of Pretoria

1.3 Goals and objectives

1.3.1 Goal of the study

The goal of the study was to explore the psychosocial experiences of the patients and their caregivers following a stroke.

In order to achieve this goal, the specific objectives were as follows:

1.3.2 Objectives of the study

- To conceptualise and describe stroke as a phenomenon
- To explore and describe the physical impact of stroke on the patient
- To explore the emotional, social, religious and economic experiences of the patients and caregivers following a stroke
- To explore the challenges of caregiving following a stroke
- To make recommendations for social workers in intervening with stroke patients and their caregivers

1.4 Research methodology

This brief discussion of the research methodology serves as a preview and a more detailed discussion is presented in chapter three. The research approach was qualitative, due to the fact that the goal of the study was to explore the experiences of stroke patients and their caregivers. The type of research was applied and a collective case study research design was used, in that the researcher wanted to gain a holistic understanding of how stroke patients and caregivers experience the aftermath of stroke (Fouché, & Schurink, 2011:320). Non-probability purposive sampling was used to select participants and the data collection technique used was that of semi-structured interviews with an interview guide, consisting of open-ended questions. Data was voice-recorded and then transcribed and analysed by thematic and content analysis.

© University of Pretoria

1.5 Limitations of the study

A limitation was the small number of participants used; however, this study aimed to create an understanding of the experiences of stroke patients and their caregivers and is not meant to be interpreted as a generalisation of the whole population.

It is worth mentioning that, although a greater number of participants might have yielded more categories, after interviewing ten participants, themes became repetitive and saturation was reached.

The majority of stroke patients interviewed were men and this might have skewed the results slightly, in that women may have had a different experience with stroke. This was because most women with stroke attending rehabilitation had aphasia and therefore could not be included in the study.

Caregivers were mostly women and their views might not reflect the views of males. This might be due to the fact that most patients were men and hence they were cared for by their wives. The views expressed by these women are also vital as women are traditional caregivers.

1.6 Presentation of the research report

The research report contains several chapters.

- **Chapter one** focusses on the general background, such as the introduction, definitions of key terms, rationale and problem statement, goal and objectives and a brief overview of the research methodology. Lastly the limitations to the study are highlighted.
- **Chapter two** is based on the literature study on stroke. It dwells on the following aspects of stroke: phenomenon, causes, treatment and theoretical framework. It includes the literature review on relevant themes that emerged from data, such as physical, psychological, social and economic implications. It describes the role of the social worker from an ecological perspective.
- **Chapter three** consists of the empirical study. It outlines the research methodology, ethical issues and the empirical findings were depicted in order to relay the experiences of stroke patients and their caregivers.

© University of Pretoria

- **Chapter four** gives the summary, conclusions and the recommendations of the study.

© University of Pretoria

2. CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Stroke is a sudden, life-changing event with life-long implications that often include chronic disability, decreased independency and increased need for medical, social and caregiver support (Eisenberg & Rashbaum, 2011:564). In order to gain a clearer understanding of how stroke impacts on the functioning of the patient and caregivers, the literature review will present a detailed discussion on ecosystems perspective as a practice framework in social work; an overview of stroke prevalence; stroke as a phenomenon; the risk factors, symptoms and treatment; as well as the holistic experiences of patients and caregivers.

The choice of the ecosystems perspective is based on its holistic approach and in the interest of encouraging social workers to adopt a broad focus, working from a comprehensive and interdisciplinary perspective, in examining the experiences of stroke patients and their caregivers. This perspective provides a framework to understand the broader influences that determine how stroke patients and caregivers deal with the aftermath of stroke.

2.2 Theoretical framework: Ecosystems perspective

The ecosystems perspective forms part of the systems theory, which conceptualises the way systems function and interact with other systems (Ross & Deverrel, 2010:305). The principles of ecosystems enhance our understanding that all phenomena are interconnected and interdependent, as well as dependent on cyclical process of nature (Gitterman & Germain, 2008:66). It provides a holistic framework within which to locate all the different elements of people's lives and the connection between them (Jack, 2010: 130). Within the ecological perspective, the holistic experiences of stroke patients and their caregivers are more likely to be a combination of multiple levels of influence, with small changes in one having the potential to generate significant influence on other systems (Ross & Deverell, 2010:18). The essential strategy to have a holistic understanding of the aftermath of stroke is to explore the entire experiences of stroke patients and their caregivers from multiple levels. These interrelated components are identified as the micro, meso, exo and macro systems (Jack, 2012:130). Integration of these

© University of Pretoria

different levels allows for an in-depth understanding of patients and their caregivers in the environmental context in which they live and act. This reminds social workers that problems encountered are a product of a combination of multiple factors rather than having a single cause. It helps social workers to understand the way in which all of the different elements of people's lives – at individual, family, neighbourhood and society levels of influence – interact together to shape their behaviour and circumstance (Jack, 2012:139).

2.2.1 Evolution and development

Besthorn, (2011:173) states that the systems theory emerged as an attempt to conceptualise a dual and balanced obligation to both person and environment. It recognised the influence of systems in the life of people. Donoghue and Maidment (2005:32) highlight that professional reaction to systems theory varied between enthusiasm, caution and resistance. The criticisms around systems theory were based on its level of abstraction and lack of prescription of interventive strategies for social workers.

In an attempt to clarify the abstraction of systems theory and its perceived lack of practical application for frontline social work practice, several authors began to introduce the field of ecology into social work theory. Carel Germain (1973) as cited in Besthorn (2011; 175) first introduced the ecological perspective to social work in part to address criticisms of the systems model. Germain understood that in order to fully enhance human well-being, the physical and social environments of persons must be assessed concurrently. According to Donoghue and Maidment (2005:34), the purpose of the ecological perspective was to help social workers customise their intervention to the person, the environment or the interaction between the two. Gitterman and Germain collaborated in 1976, and later in 1980, 1996 and 2008, to develop the life model, which elaborates the ecosystems perspective. The life model aims to improve the level of fit between people's perceived needs, capacities, and aspirations, and their environmental supports and resources (Donoghue & Maidment, 2005:35).

© University of Pretoria

Another significant influence on social work ecological perspective was the work of developmental psychologist, Urie Bronfenbrenner (1973, 1979). His ecological systems theory posited five types of nested systems which are in constant interaction with one another and which shape human development. He described these interrelated elements as the microsystems, mesosystems, exosystems, macrosystems and cronosystems. For Bronfenbrenner, people are in active participation in their development, and the way they perceive their environments is often as important as the way they actually experience their environmental context (Besthorn, 2011: 175; Donoghue & Maidment, 2005:37).

Meyer's (1979) ecosystems perspective emerged out of a search for a coherent unifying theory for social work, rather than an attempt to enrich systems theory. The ecological perspective drew professional attention not only to persons in the environment but also to the dynamic interaction of persons in the environment (Besthorn, 2011:176; Donoghue & Maidment, 2005:37).

From the above, it can be deduced that the ecological perspective, the life model and the ecosystems perspective have shaped the emergence of ecological social work.

2.2.2 Key ecological concepts

The Ecological Systems Theory in social work adapted concepts from both the systems and ecological theories (Hepworth, Rooney, Rooney & Stroom-Gottfried, 2013:16).

ECOLOGY: The study of ecology seeks to understand the reciprocal relationship between organisms and the environment, person-and-environment-fit and adaptation and adaptedness (Gitterman & Germain, 2008:51). The ecological metaphor, as indicated by Ross and Deverell, (2010: 305), draws upon ecological concepts to describe the interdependencies and exchanges among people and social systems.

PERSON ENVIRONMENT FIT: "central to the interrelationship and adaptation, people strive to deal with and improve the *level of fit* with their environments. Level of fit is concerned with the degree of balance and reciprocity between the person's

© University of Pretoria

needs, capacities and aspirations, and the resources accessible and available in their environments'' (Gitterman, 1996a in Donoghue & Maidment, 2005:39). Both the individual and the environment experience change, as one gives and the other one takes, or vice versa. Reciprocal adaptation occurs when individuals develop through change and environment supports this change.

HABITANT AND NICHE: Hepworth et al. (2013:16) identified two concepts (habitant and niche) that are especially relevant to social work and which assist in understanding the impact of the environment on people. Habitant refers to "the location where a person or organisms live and, in the case of humans, consists of the physical and social settings within a particular cultural context. When habitants are rich in the resources required for growth and development, people tend to thrive. When habitants are deficient in vital resources, physical, social and emotional development may be adversely affected". This suggests that stroke patients with supportive social networks of friends, relatives, church associates and neighbours might mitigate the negative effects of stroke.

Hepworth et al. (2013:16) describe Niche as "the status or roles occupied by members of the community". In order to achieve self-respect and a stable sense of identity, people need to find their niche in society. Donoghue and Maidment (2005: 40) posit that a niche can be either entrapping or enabling. An entrapping niche is one in which people are marginalised with no resources and little prospect of social mobility or belonging. An enabling niche provides resources and support that enables social mobility, social belonging and social connectivity.

STRUCTURE: This is another key concept that "involves the system's pattern of organisation which guide and maintain its functioning. Within each system there are subsystems, and every individual is also part of the bigger system or suprasystem. Systems are differentiated by boundaries, non-physical dividers that separate one system from another. Boundaries vary in type and in the amount they receive and transmit. Generally, problems occur when boundaries are either too open or too closed" (Donoghue & Maidment, 2005:40).

ECO-MAP: This is a tool for assessing personal and social networks. It provides a very effective tool for aiding communication with people across a wide range of

© University of Pretoria

ages and capacities, helping to visually identify some of the strengths and weaknesses that exist within a person's social network (Hepworth et al., 2013:325).

The above mentioned concepts provide a foundation for the ecosystems approach and they are highly relevant to understanding reciprocal interaction between stroke patients and their environments.

2.2.3 The ecological perspective as a context in understanding stroke

Ross and Deverell (2010:306) suggested that the ecological perspective demonstrates that the functioning of an individual is largely dependent on his/her environmental context. It posits that people shape the environment and in turn are being shaped by the environment. It makes clear that individuals and their environments can never be understood separately (Jack, 2012:130). As a result of this interdependence, the researcher will be able to understand how a stroke patient and their caregiver adapt to the environment in order to cope, survive and compete for needed resources.

Within the ecological perspective, the holistic experiences of stroke patients and their caregivers are understood to be dependent on the interplay between strength and vulnerabilities in the various settings, including other family, friendship network, work situation, neighbours, the wider community and the society which they belong to. These interrelated components are identified as the macro, exo, meso and micro systems. Bronfenbrenner, quoted by Engstrom (2012:167), provides a compelling framework for understanding interdependencies and exchanges among and between people and different systems. According to this perspective, each individual experiences life within a unique intersecting web of systems.

It is thus vital for social workers who want to provide effective intervention to consider multisystem influences. The ecological framework provides an efficient way to consider the numerous systems with which stroke patients interact

© University of Pretoria

2.2.3.1 Macrosystems

An overview of an ecological approach to assessment starts with macrosystems and concludes with in-depth attention to aspects of the microsystems. Beginning with the macrosystems, it places social and environmental considerations in the foreground of the assessment and intervention processes (Engstrom, 2012:169).

At a macro level, stroke is emerging as a leading cause of preventable death and disability in adults (Lemogoum, Degaute & Bovet 2005: 95). In SSA, infectious diseases such as HIV/AIDS and malaria are dominant; hence there is apparent reluctance on the part of health funding agencies and policy makers to divert attention or resources away from these major health problems and direct them towards stroke (Kengne & Anderson, 2006:180).

Lemogoum et al. (2005:95) state that the high incidence of stroke in SSA and SA is largely linked to the adoption of detrimental lifestyle choices such as unhealthy diet and tobacco use. It is also related to limited health facilities and uncontrolled risk factors such as hypertension and race/ethnicity. They argue that low prevalence of awareness, treatment and control of hypertension poses a serious challenge for stroke prevention in SSA. Same authors further suggest that reducing the stroke burden globally will require public health programmes and health policy to increase awareness on the preventable nature of stroke, educate on the modifiable risk factors of stroke, enable environmental changes, enable the adoption of healthy lifestyles and strengthen risk factor reduction among persons at high risk. A strong political commitment is necessary to foster relevant policy and environmental changes to support adequate education and prevention programmes.

In SA, the Draft White Paper on Mainstreaming of the Rights of Persons with Disability to Equity and Dignity (Dept. of Social Development, November, 2014) advocates for a coordinated, multi-sectoral, interdisciplinary approach in designing programmes that affect major societal groups. Implementing this in practice is still a challenge as resources for stroke care and awareness of the disease are still deficient, particularly in rural areas (Wasserman, De Villiers & Bryer, 2009). The stroke unit model of care has not been widely implemented and there are no minimum requirements for treatment stipulated, and protocols for stroke care have not been developed at most hospitals and districts as stroke is not seen as a

© University of Pretoria

strategic priority, owing to lack of funding (Bryer, Connor, Haug, Cheyip, Staub, Tipping, Duim & Pinkney-Atkinson, 2010:756).

The cultural context of stroke is another element in the macro environment to take into consideration. Every culture includes belief systems that help members predict, diagnose, prevent and treat many health problems (Fouché, 2005:55). This is shared by Engstrom (2012:169) who elucidates that a person's cultural context informs their frame of reference and influences how they will identify and label problems. In addition, cultural influences may shape the experiences and communication of pain, expected or desired treatment, and understanding of the illness's causes, coping styles and perspective regarding who to turn to for help.

In some cultures, sicknesses like stroke are perceived to be caused by evil spirits and not treatable by physical means (Ross & Deverell, 2010:14) and they will look to alternative medicine such as traditional healers or herbalists for health care (Fouché, 2005:55). With regard to stroke patients and their caregivers, social workers should consider specific ways in which cultural background influences their own and their client's values regarding expression of distress or emotions. The assessment should consider to what degree a person's cultural background encourages open expression of emotions or limits its direct expression (Engstrom, 2012:170).

There are various studies that suggest that actively considering the client's spiritual beliefs can contribute towards the provision of culturally competent services. Spiritual beliefs and health beliefs are intertwined and warrant attention that is comparable to that given to other cultural beliefs. Spirituality can shape beliefs and provide strength during times of adversity (Hepworth et al., 2013:226).

Walch (2002), as cited in (Engstrom, 2012:171), describes the role of prayer, meditation, and faith in numerous positive health outcomes, including reduced stress, decreased blood pressure and improved management of chronic pain. Beliefs may provide a powerful source of cognitive assistance to people experiencing physical and mental difficulties.

From the preceding discussions, it is evident that efforts that are made at the macro level to address stroke issues are not yet adequate. Factors such as lifestyle, diverse cultures and religion still render these efforts futile. The SA government faces the dilemma that prioritising stroke is difficult while HIV is still depleting most of its resources.

© University of Pretoria

2.2.3.2 The ExoSystems

The processes within, and relationships between, systems impacting on stroke patients is the next level of assessment. In addition to the overall lack of resources in social service provision in South Africa, people living in impoverished areas often experience limited access to social services and medical resources (Fouché, 2005: 57). Bryer et al. (2010:775) argue that there is poor access of patients to rehabilitation services and little information on available resources in the community. Resources for stroke care are scanty, particularly in rural areas. More disturbing is the fact that patients with acute stroke are often discharged from hospital without the option of receiving adequate rehabilitation by trained staff, and those in outpatient therapy rarely receive the intensive therapy of inpatient rehabilitation units.

It is acknowledged by Bryer et al. (2010:775) that the majority of stroke patients in SA are treated in the public health care, where there is currently a shortage of resources. In-patient rehabilitation facilities in the public sector are few and are located in urban areas, and demand for beds exceeds supply. The number of rehabilitation professionals to cope with the burden of stroke patients and their needs is inadequate, and therefore patients are unable to attend regular clinic or hospital-based rehabilitation sessions.

The national stroke strategy (DH, 2007), in Steyn (2007), is in disagreement. It notes that a range of services are available that are accessible and support the long-term needs of individuals and their caregivers. In contrast, Edmas (2010:178) argues that it can take a long time to track down a service where someone will come and sit with the patient while the caregiver goes out. In reality such services are patchy and not specific to stroke. Access to home-based care and community rehabilitation services varies considerably in different provinces and districts, depending on geographical location and availability of therapists.

2.2.3.3 MesoSystems

Attention to client's family and social context reflects the mesosystem from an ecological perspective (Engstrom, 2012:175). Meso level factors of stroke from an ecological perspective require assessment of social support for both the stroke patient and their caregivers. A number of factors determine an individual's ability

© University of Pretoria

to recover or adapt after a crisis or an illness. One of these factors draws on evidence that individuals with strong social ties are more likely to alter behaviour and attitude than those with weaker social connections, and that the behaviour and attitude of family and friends have a powerful effect on the behaviour of individuals (Fouché, 2005: 58).

It is thought that social support has the capacity to buffer people from the negative consequences of potentially stressful events and can provide people with a sense of acceptance and self-worth (Hepworth et al., 2013: 225). Gitterman and Germain (2008: 244) add that social networks can cushion an individual through four types of support, namely instrumental (goods and services such as financial and material resources), emotional (which provides a sense of self-worth and acceptance – nurturance, empathy), informational (advice and feedback), and appraisal (information relevant to self-appraisal). As part of a comprehensive assessment, social workers should explore a client's social support, including attention to composition and size of the person's social network, types of social support available and strengths and obstacles to engaging and sharing with others (Hepworth et al., 2013: 225).

A large body of literature (Hepworth et al. 2013: 463; Ross & Deverell; 2010: 159; Rolland, 2012: 318) attest to the importance of assessing the impact of diseases on families and the relationship of family dynamics to illness behaviour, adherence and disease course. The relevance of ecological systems perspective in this current study is equally based on previous studies that have attested to the link between the recovery rate of stroke survivors and the empathy and understanding of family members and the wider community (Ross & Deverrel, 2010: 335).

Fouché (2005: 58) asserts that many social work interventions on the meso level are aimed at helping families find enhanced linkages between the family and its environment, or facilitate the sharing between groups. Assessment on the meso level should identify systems that influence family relationships and interaction patterns (Hepworth et al., 2013:463). With regard to the assessment of mental and physical health in the context of family and social relationships, Engstrom (2012:175) believes that it is important to pay attention to the meaning, diversity and strength of these relationships.

© University of Pretoria

Hepworth et al. (2013:325) and Donoghue and Maidment (2005:32), both mentioned the eco-map as a useful tool for a social worker. Eco-maps identify and organise relevant environmental factors outside of the individual or family context. They are useful in clarifying the supports and stresses in the client's environment, revealing patterns such as social isolation, conflicts, or an unresponsive social system.

2.2.3.4 Microsystems

The microsystem deals with the individual as a client system. Intervention on this level focusses either on the stroke patients themselves or on the caregivers and it needs to embrace not only the physical consequences, but also the psychosocial aspects of recovery from a multidisciplinary team perspective (Muller, 1999 in Ross & Deverell, 2010:165). Psychosocial support at the micro level, as outlined by Gardner and Werner-Lin (2012:510), includes:

- conducting comprehensive assessment of individual and family emotional, behavioural, and social functioning;
- providing emotional support, encouragement and counselling – assessing patient and family coping, and social resources, and response to illness;
- educating and providing answers about medical, practical, and psychosocial aspects of the disease;
- fostering adaptive coping and helping patients and families navigate complex health care and community systems;
- mobilising supportive resources and services to improve quality of care;
- teaching strategies to manage medical regimes and to reduce symptoms; and
- providing supportive and therapeutic interventions to individuals, groups and families to address uncertainty, reduce anxiety and emotional distress, and enhance quality of life throughout the illness course.

The discussion above highlights the importance of continuity of interventions from macro until micro when dealing with stroke patients and their caregivers.

© University of Pretoria

Integration of these different levels allows for an in-depth understanding of patients in the environmental context in which they live or act.

In conclusion, the researcher's decision to use the systemic ecological approach is informed by the fact that it moves beyond the individualistic orientation common to other studies, and rather enables the researcher to explore the experiences of stroke patients and their caregivers working from a holistic approach. It assists to tap and unpack experiences, taking into account the multi-dimensional effects of stroke in terms of the environment and social influences. In adopting the ecosystems perspective, exploring how change in one part of the system (stroke patients), affects all parts of the system (broader society), becomes essential. It also provides participants and the researcher the opportunity to explore resources available in the community and other avenues available to help them.

2.3 Prevalence of stroke

A stroke is a lifestyle disease that is prevalent and causes death and disability. It is the third leading cause of mortality in the United States after cardiovascular disease and cancer, accounting for 10% to 12% of all deaths. Globally, stroke is the second leading cause of mortality in developed nations with 4,5 million deaths every year. An estimated 550 000 strokes occur each year, resulting in 150 000 deaths and more than 300 000 individuals with significant disability (Bartels, 2011:1). In some countries in SSA, stroke mortality and case fatality exceed those in the developed world (Lemogoum et al., 2005:95).

Stroke and other chronic non-communicable diseases associated with lifestyle and demographic transitions occurring all over the world is increasingly being acknowledged. However, the significance of these trends is considerably overshadowed by the attention given to the impact of human immunodeficiency virus and infectious diseases in SSA (Kengne & Anderson, 2006:180). In an attempt to address this gap, Kengne and Anderson undertook a literature review of the burden of stroke in SSA. The hospital-based data and limited community surveys broadly indicate a high and increasing rate of stroke, affecting people at much younger ages in SSA than in developed countries.

© University of Pretoria

In SA, the incidence of stroke is expected to rise in the future as the population undergoes health transition. Presently, understanding the burden and nature of stroke in South Africa is complicated because of different population groups and the socio-economic structure (Connor & Bryer, 2005:195). However, stroke was declared a catastrophic illness in South Africa on the 26 October 2007, at a historic ceremony of the Joint World Congress of Stroke. Stroke was also rated as the forerunner of vascular disease in health transition, which results in a high level of disability and the majority of those cases are cared for at home (Connor & Breyer, 2005:199). This will unfortunately put strain on the health system and the caregivers (Bartels, 2011:2).

The Southern African Stroke Prevention Initiative Study (SASPI, 2004) has compared the prevalence of stroke survivors who required help with at least one activity of daily living, with similar figures from Tanzania and New Zealand. There were far more stroke survivors in rural South Africa than in Tanzania, and about the same number as in New Zealand, which has a higher population with a higher incidence of stroke than in South Africa. Reasons for the high number of people who suffer from disability due to stroke are not clear. Various factors might have contributed to this result, such as inadequate rehabilitation services or unwillingness of patients to receive rehabilitation or to complete rehabilitation owing to the fear of being denied a disability grant if fully rehabilitated (Bryer et al., 2010:755).

Given the above statistics, stroke seems to be a global health problem that needs immediate intervention. It can also be concluded that the prevalence of stroke is increasing in South Africa. Multifactorial issues such as diverse population and socio-economic aspects contribute to the increase and difficulty in understanding the clear burden of stroke. However, what is more evident is that stroke survivors who need care, are more numerous in SA than in neighbouring countries. It is therefore important to have an understanding of stroke as a phenomenon, so as to be able to identify the symptoms quickly and prevent further disabilities.

© University of Pretoria

2.4 Description and definition of stroke syndromes

2.4.1 Stroke

As noted by the National Stroke Association (2009) in Eisenberg and Rashbaum (2011:550), “a stroke occurs when a blood clot blocks an artery or a blood vessel break, interrupting blood flow to the brain, leading to brain cell death and resultant brain damage”. When cells die during a stroke, abilities controlled by that area of the brain are lost, which may include speech, memory and movement. Strokes are described as either minor/reversible or major/irreversible. Minor strokes include transient attacks which last less than 24 hours, whereas a major stroke is any cerebral vascular accident. It is a heterogeneous condition consisting of haemorrhagic and ischemic attacks (Bartels, 2011:2).

2.4.2 Transient Ischemic Attack (TIA)

TIAs are temporary attacks that come on suddenly and last for a few minutes and not more than 24 hours. Although they often are not recognised as such, they are a warning that a complete stroke may occur. During the attack the person may feel a weakness or numbness on one side of the body, slurring of speech or inability to talk, visual disturbances such as blindness or double vision, and uncoordinated walking. These symptoms are short-lived and reversible. The probability of a complete stroke occurring five years after a TIA is 35% (Bartels, 2011:2).

2.5 Causes of stroke

According to Lezak, Howieson and Loring (2004:196), the word stroke applies to both ischemic and haemorrhagic cerebro-vascular diseases, with either permanent or transient symptoms. Ischemic strokes are those that are caused by interruption of blood supply leading to infarction of tissue and cell injury. Haemorrhagic strokes are the ones which result from rupture of a blood vessel or an abnormal vascular structure. Ischemic strokes are divided into embolic and thrombotic types. Lezak et al. (2004:197) define embolic strokes as those that are caused by migration of materials to central nervous system blood vessels from some distant source, causing vascular occlusion and ischemia of brain tissue. These can consist of air, fat or other material introduced into the circulatory system. About 20% to 30% of obstructive strokes are embolic. Cerebral thrombosis is the build -up of fat deposits within the artery walls. These deposits

© University of Pretoria

are the most common source of obstruction of blood flow to the brain, causing 60% to 70 % of all strokes and 75 % of obstructive strokes.

In South Africa, ischaemic strokes caused by an embolus or thrombosis accounts for 85% of all strokes, whereas 15% are haemorrhage strokes caused by the rupture of a cerebral vessel with bleeding into the brain (Bryer et al., 2010:750). For the purpose of this study, stroke is a brain attack resulting from a blockage or ruptured blood vessel, in which the individual presents with different impairments. Minor or reversible strokes are not included in this study.

2.6 Risk factors

A stroke is essentially a preventable disease with known, manageable risk factors. The risk factors for stroke may be modifiable or non-modifiable (the latter include factors such as increasing age and male gender). The established risk factors for stroke include hypertension, cigarette smoking, obesity, diabetes and the use of contraceptives high in oestrogen. The incidence and prevalence of stroke is high among diabetic and hypertensive patients, according to Bartels (2011:2).

The South African comparative risk assessment group (2007), estimated the relative prevalence of eight risk factors that contribute towards stroke. These include hypertension (52%), diabetes (8%), high cholesterol (15%), and cigarette smoking (24%). High blood pressure was found to be the most common modifiable risk factor for stroke in all population groups (Bryer, et al. 2010:755). Other risk factors added by Eisenberg and Rashbaum (2011:550) include atrial fibrillation, old age, and transient ischemic attack. All these risks factors increase with age and are higher in men than in women. For each consecutive decade after 55 years of age, the risk of stroke doubles.

The majority of the abovementioned risk factors can be prevented and avoided, hence it can be concluded that stroke is a lifestyle disease that can be prevented. This means education to combat these lifestyle diseases is essential. It is also imperative for early detection of the exact causes of stroke, so as to get timeous assistance; hence identification of possible symptoms is vital. The text below highlights signs and symptoms that a patient might present with.

© University of Pretoria

2.7 Symptoms of stroke

Steyn (2007:3) asserts that stroke symptoms depend on the area of the brain affected. Stroke symptoms typically start suddenly, over seconds and minutes, and in most cases do not progress further. The more extensive the area of the brain affected, the more functions that are likely to be lost. Clinical features will also vary with the severity of damage and the extent of collateral circulation that develops to help the brain compensate for decreased blood supply. If the CVA occurs in the left hemisphere, it produces symptoms on the right side and vice versa. However, a CVA that causes cranial nerve damage produces signs of cranial nerve dysfunction on the same side as the haemorrhage.

Edmas, (2010:2) summarised these symptoms as sudden numbness and weakness of the face, the arm, or leg – especially on one side, sudden confusion, trouble speaking and understanding, sudden trouble seeing in one or both eyes, sudden trouble walking, dizziness or loss of balance or coordination, and lastly, sudden severe headache with no known cause (Eisenberg & Rashbaum, 2011:553).

Patients describing or demonstrating these symptoms should be referred for prompt medical evaluation. Knowledge of these symptoms will be useful in helping patients to avoid disability or death from stroke. The possibility that the patient might present with stroke-like symptoms warrants proper diagnosis to ensure that relevant treatment will be given. The aspects of clinical evaluation that are important in assessment of stroke are discussed below.

2.8 Diagnosis of stroke

Diagnosis of CVA is based on observation of clinical features, a history of risk factors and the results of diagnostic tests. The diagnosis of stroke is clinical, with assistance from imaging techniques. The diagnostic procedures as described by different authors include:

2.8.1 Physical examination

Bryer et al. (2010:762) indicate that examination of the body to check symptoms and neurological status is important. Physical examination should include the

© University of Pretoria

proposed system advocated by the National Stroke Association. This system includes FAST STROKE diagnosis (Edmans, 2010:2). The acronym FAST stands for:

- Face – sudden onset weakness of the face indicate a problem;
- Arm – if a person, when asked to raise both arms, involuntarily lets one arm drift downwards;
- Speech – is the speech slurred or strange?; and
- Time – immediate medical attention should be given.

Edmans (2010:762) stresses that other physical investigations should include assessment of symptoms such as lack of co-ordination, headache, drooling, mental status changes, numbness, gait problems, seizure activity, swallowing, visual change and speech problems. A mental status examination determines a patient's level of alertness and consciousness.

Eisenberg and Rashbaum (2011:553) maintain that questioning should include determination of the patient's age, as well as the time and onset pattern of the events. Evaluation of past medical history and risk factors for stroke, such as hypertension, diabetes mellitus, obesity, cigarette use, recent trauma, atrial fibrillation and prior neurological disorders, should be done and followed by laboratory tests.

2.8.2 Laboratory tests

Electronic studies or brain imaging, using computerised Tomography (CT), Magnetic Resonance Imaging (MRI), Magnetic Resonance Angiography (MRA) and Transcranial and Caratoid Doppler, distinguishes ischaemic stroke from intracranial haemorrhage and identifies other stroke mimics (Edmans, 2010:6–12).

It is worth mentioning that although this diagnostic equipment is essential, cost constraints and limited availability of laboratory tests in SSA and SA restrict patients' access to these kinds of services. According to Kengne and Anderson (2006:181), in many hospitals, CT scan, for example, is only performed on about half of all patients presenting with stroke, and usually only on those who can afford

© University of Pretoria

it. In SA, only academic hospitals have CT scans. As a consequence, not all patients will have the exact type of stroke diagnosed. However, after the diagnosis has been made, the family needs to understand the prognosis and possible treatment options available. The next section will illustrate the prevention, treatment and management of stroke.

2.9 Means of prevention and treatment of stroke

2.9.1 Prevention of stroke

The choice of prevention and treatment is governed by the condition that predisposes the patient to having a stroke and the possibility that he/she will benefit from treatment. Medical prevention measures are aimed at eliminating or controlling atherosclerosis and other conditions that cause stroke. Since there is an association between stroke and hypertension, heart diseases and transient ischemic attacks, prevention usually starts by addressing these risk factors (Bartels, 2011:18).

Ross and Deverell (2010:162) support the idea that detection and treatment of hypertension is the most important strategy of preventing stroke. They believe that persons suffering from hypertension must restrict their salt and fat intake, reduce alcohol consumption and reduce stress. They need to express their dissatisfaction in a calm and constructive way. Efforts to control diabetes and cholesterol levels through diet and exercise, weight reduction, and cessation of smoking are also factors that reduce the risk of stroke.

2.9.2 Drug treatment

Edmans (2010:8-9) and Bartels (2011:18–19) highlight different treatments for various stroke symptoms. Medications useful in the treatment of CVA include antiplatelet treatment with aspirin, or full anticoagulants such as heparin or warfarin may be used in patients with ischemic stroke. In patients with intolerance to aspirin or who experience stroke while on aspirin, clopidogrel is an alternative for prevention. Anticoagulant therapy is only used when haemorrhage has been ruled out as a cause, because it increases bleeding tendencies. It is used when

© University of Pretoria

clot formation has been found to be the potential cause of decreased blood flow. It does not dissolve the existing thrombus, but only prevent extensions. Antihypertensive drugs are used to reduce pressure within the blood vessels and to avoid rupture. Other agents that reduce cerebral oedema include cortisteroid, mannitol and glycerol.

2.9.3 Surgical treatment

Patients who have suffered stroke may benefit from surgical procedures such as carotid endarterectomy. This operation to widen the internal carotid artery is recommended for patients with a stenosis of greater than 70% with reasonable function status and salvageable brain tissue in the vascular territory under consideration (Bartels, 2011:17; Edmans, 2010:9).

2.9.4 Rehabilitation

Rehabilitation, as defined by Harwood, Huwez and Good (2011:178) is “the restoration of individual’s capacity to achieve the optimal ability to function, both physically and cognitively”. They highlight three main elements in rehabilitation which are enablement, resettlement and readjustment. Enablement is the restoration of function, learning of new skills and making use of aids and appliances. Resettlement is the adaptation to the environment to maximise the participation of patients. Readjustment is the psychological adaptation and re-establishing esteem and fulfilment. This means that patients engage in activities that will help them to return to normal life as much as possible by regaining and relearning the skills of everyday life. The patient should be helped with the things they cannot do, but should gradually be trained in activities such as bathing, feeding and dressing to encourage independence.

Rehabilitation aims to help the survivor understand and adapt to difficulties. The rehabilitation team will include nurses; doctors; occupational, physical, and speech therapists; psychologists; and social workers that specialise in various aspects of rehabilitation. Each discipline completes a functional assessment and develops a plan of treatment congruent with the goals set by the patient, caregiver and therapist (Harwood et al. 2011:185).

© University of Pretoria

The various advanced treatment options discussed above have fortunately decreased death rate due to stroke in SA; hence, the number of stroke survivors has greatly increased and also the demand for care has increased. However, stroke patients and their families and caregivers will experience different consequences of living with stroke that will be discussed below.

2.10 Holistic effects of stroke on the patient

After a lifetime of normal functioning, stroke has profound effects on the quality of life of the patient. The individual will experience many diverse physical, emotional, social, financial and spiritual responses that may lead to major changes. The text that follows aims to increase understanding of this process of change following a stroke.

2.10.1 Physical and medical aspects

While the cause, onset of illness, and degree of disability may differ, the person who has suffered a stroke may experience many physical adjustments during rehabilitation. According to Ross and Deverell (2010:157), the patient and the family will have to manage many physical disabilities that restrict mobility and position, such as hemianopia (restriction of visual field to one side of the body), hemiplegia (motor problems associated with paralysis of one side of the body, agnosia (loss of ability to perceive and attach meaning to incoming stimuli), apraxia (loss of ability in programming, initiating and sequencing motor behaviours) and decreased capacity for self-care. Ross and Deverell (2010:158) added aphasia as one of the disorders resulting from stroke that affects one side of the brain where language function is obtained. This condition has a great impact on the stroke patient and their family because the patient cannot communicate their needs and wants.

The individual who is paralysed from a cerebral vascular accident is frequently coping with other pre-existing chronic illnesses, such as **atherosclerosis**, **diabetes mellitus** or **hypertension**, that preceded stroke. The person may suffer from a single disabling event or from multiple infarcts that lead to disability. Since infarcts decrease blood supply to the brain, mental status changes, such as **acute**

© University of Pretoria

confusion, **memory loss**, and **dementia**, may occur, as well as mood disorders such as **depression** (Harwood et al., 2011:82).

Eisenberg and Rashbaum (2011:554–556) also highlight the following medical complications of stroke:

- **Urinary incontinence and bowel dysfunction** "occurs in about 30% to 80% of stroke patient during the early stages. It continues in only about 10% of patients two years after the stroke. Incontinence and bowel dysfunction may be related to weakness, cognitive perceptual impairment and lack of mobility. Transferring onto a toilet and adjusting one's clothing are often difficult tasks for a stroke patient. Incontinence and bowel dysfunction may result in urinary tract infection, skin breakdown, frustration and social embarrassment".
- **Pressure sores** are also the "direct result of immobility and skin insensitivity. Other factors such as moisture, infection and inadequate nutrition play a role. Skin inspection, appropriate bladder and bowel regimes and body position changes are extremely important to prevent pressure sores".
- **Dysphasia or disorder of swallowing** function remains the most significant dietary concern after stroke. Stroke may cause dysphasia by leading to impairment in oral motor control. Untreated dysphasia may lead to pneumonia and malnutrition.
- **Falls** are of particular concern in stroke survivors. These patients are at increased risk of hip fracture because of developed osteoporosis, and acuity of their balance, visual perception, and spatial perception is decreased.

All the above mentioned physical effects of stroke were confirmed by Lee, Chen and Hseuh, (2010) who explored the impact of stroke from the perspective of patients in Taiwan. The study highlighted that the factors which patients perceived to impact them the most were physical aspects, including mobility, apraxia, aphasia, dysphasia and hand functioning. Arm functioning and mobility are physical factors that affect the functions and activities essential for the patient in

© University of Pretoria

their daily lives. Restrictions to either of these factors might lead to poor quality of life, hence they recommend further research to understand the impact of stroke on an individual's adjustment at home and in the community. This was responded to in a study done by McCarthy, Powers and Lyons, (2011:140) who found that stroke survivors frequently experience physical problems such as impaired balance, compromised mobility, restricted range of motion, partial or complete paralysis in different regions of the body, and fatigue. Cognitive and sensory impairments include numbness, chronic pain, impaired memory, loss of executive functioning and dementia.

Given the results of the abovementioned studies, it is not surprising that the researcher in this current study chose to study the effects of stroke holistically, including all aspects of a patient's life. It is evident that if one of the physical components is compromised, then functioning is affected, which might lead to various emotional, social and economic situations that affect the quality of life of the patient.

2.10.2 Emotional reactions

A stroke is an emotional event for individuals who lived previously normal lives. As noted by Haslam et al. (2008:672), the onset of stroke entails deterioration of physical and mental ability which consequently threatens emotional well-being. During the acute phase, individuals feel overwhelmed in experiences of loss of control over personal care, which affects their sense of dignity (Falk-Kessler, 2011:51). It is expected that the initial realisation of disability may evoke a strong emotional reaction and grief process. Harwood et al. (2011:300) define an emotion as "a mental and physiological state associated with feelings, thoughts, and behaviours, such as vulnerability, lack of confidence, anxiety, depression or anger."

It has been suggested by Falk-Kessler (2011:21), that a patient's reaction to disability, loss of function, change in body image, role changes and possible social alienation can give rise to reactions of grief, anger, guilt and fear. All of these reactions contribute to a sense of social stigma and produce feelings that contribute to depression and anxiety. However, the literature has identified various

© University of Pretoria

models of adjustment to assist patients to have a successful transition from being healthy individuals to being a person with disabilities. Brashler (2012:226), said that the stage model of adjustment to disability are derived from Kübler-Ross's (1969) work with terminally ill patients. This model suggests that a person with a disabling condition might progress through predictable stages or reactions, namely shock, relief, denial, bargaining, guilt, depression, anxiety and acceptance. Most importantly, it is necessary to note that the reaction will differ from one individual to another and will not necessarily progress in the same sequence.

With regard to another adjustment model, Brashler (2012:226) highlights that the grief model compares reactions to disability with the process of bereavement following death. Mourning is defined as "the adaptation of loss (Worden, 1991) and can have relevance to the loss of a limb, the loss of function, or the loss of a dream". Bartels (2011:21) asserts that, after a stroke, patients may go through the four stages of bereavement as described by Worden. These include accepting loss, experiencing the pain of the loss, adjusting to a new environment in which previous abilities are missing, and investing in the new environment.

Several authors (Bartels, 2011:21; Falk-Kessler, 2011:55) agree that **denial** is a normal defence mechanism as long as it does not interfere with the rehabilitation process. It is a stage where individuals may be unable to move on as they attempt to make sense of their disability. It protects individuals from overwhelming emotions and it negates the reality of what is happening.

Bargaining is usually the second stage where the patient hopes for full recovery and may tap into their spiritual beliefs as a source for bringing about change in the situation (Inniss, 2011:623). It is used as an attempt to delay acceptance of the illness, to revert from present to the past. Ross and Deverell (2010:53) further postulate that this stage is characterised by fantasy thinking. Bargaining usually involves the promise of good behaviour in return for good health. Same authors point out that patients who experience **anger** usually feel envy for those who are still healthy. The patient's anger is sometimes interpreted as a death wish, especially by spouses of persons who have suffered a stroke (Ross & Deverell, 2010: 55).

© University of Pretoria

Bartels (2011:22), indicates that **depression** is highly prevalent after a stroke, developing in 20% to 50% of stroke survivors. Moses (in Ross and Deverell, 2010:158) defines depression as anger turned inwards, towards oneself. Both authors elucidate that it is important to distinguish between depression that has generated and related to some sort of chemical imbalance in the body, and reaction depression which is a normal response to a traumatic experience. Depression that has a direct organic cause (primary depression) has its onset in the acute stage (0–3months) following stroke, and results directly from structural lesions to the brain. Depression that occurs reactively as part of the grieving process (secondary depression) may develop within six months post stroke. Individuals with secondary stroke grieve for their loss of function, loss of former network support, job, income and independence (Ross & Deverell, 2010: 55,158). This type of depression is a normal process of grieving as long as it does not continue for too long. It allows individuals to separate themselves from dreams and fantasies. Added to these, post-stroke depression is characterised by sadness, worthlessness hopelessness, loss of pleasure in activities, change in appetite, weight and sleep patterns, loss of concentration and suicidal ideation (Falk-Kessler, 2011:53).

Acceptance, according to Harwood et al. (2011:304), is “the psychological process of coming to terms with the new reality, the setting of new goals and re-integration to social life”. Many patients come to acknowledge the loss both to themselves and the world at large. According to Falk-Kessler (2011:52) the transition includes the development of optimal independence, adjustment to a new body and rebuilding of a social system. Although people still experience pain and grief, the disorder no longer overwhelms them but it is integrated into a new life perspective with new values.

There are other emotional reactions to brain damage which have been observed in many patients. Ross and Deverell (2010:158) acknowledge that cerebral infarction is accompanied by “ego” infarction, meaning that the lesion affects the patient’s self-esteem. The visible reminders of impairment, such as hemiplegia, facial paralysis and movement abnormalities, can erode the person’s body image. Feelings of loss of control, tearfulness, anger, frustration, general anxiety,

© University of Pretoria

rejection and hopelessness are also common in patients with stroke. Patients grieve for their lost functions and independence.

It is because of the enormity of the devastating effects of stroke that much attention of stroke researchers has been on the emotional aspects of stroke. Santos, Caeiro and Ferro (2006:357), investigated the presence of anger, aggression and hostility in patients. It was found that stroke patients present with anger and hostility, precipitated by a brain lesion, to which physiological and psychological dimensions also seem to contribute. This discovery is congruent with another research study by Thompson and Ryan (2009), which investigated post-stroke experience and found that emotional difficulties such as frustration, depression, anger and anxiety are present in stroke patients. In the same vein, Lee et al. (2010), in their studies, have found that patients' emotional status and productivity have been severely impacted by stroke. Surprisingly, 34% of patients reported relatively low levels of negative impact on their moods. This finding appears contrary to many studies suggesting that stroke patients have a tendency to experience more negative moods than the general population. Despite the discrepancies, they acknowledge that negative moods can affect functional status and result in poor rehabilitation. This discrepancy emphasises that one cannot assume that patients will have the same common reaction and attitude, hence thorough assessment is crucial.

2.10.3 Social aspects

In addition to the physical and emotional consequences of stroke, there are also common social reactions that have been observed, namely those aspects of behaviour that have interaction and social consequences (Ross & Deverell, 2010:161). These social aspects are multiple and complex, hence managing activities of daily living at home and in the community are often daunting for the patient (Ross & Deverell, 2010:559).

Edmas (2010:181) postulates that people who have had a stroke often feel dependent on others and are socially isolated. Usually, patients lose the social support they had before the stroke and participation in leisure activities decreases after stroke. Many social and leisure activities require transport to get to an event

© University of Pretoria

or to get supplies. Half of all stroke patients do not get out of the house as much as they would like. This is evident in the study conducted by Thompson and Ryan (2009) which investigated the consequences of stroke on the patient and their caregivers. Interviewees reported a number of ways in which a stroke had affected their daily lives, including difficulty leaving the house, doing house work, pursuing former leisure activities, washing, bathing and dressing. In all these areas, patients described the loss of social contact that accompanied these changes, and the loss of valued roles which they had previously performed. All participants perceived stroke as a life-changing event that affected them on all levels (Thompson & Ryan, 2009:1801). This is an indication that stroke should be approached holistically.

Added to these social impacts, studies conducted by Lee et al. (2010) highlight that participants were disheartened by the fact that stroke took away their enjoyment of playing with their grandchildren. This deterioration of ability to take care of grandchildren is perceived by participants as incompetence and results in dissatisfaction.

With reference to spousal relationships, almost all stroke literature has established a decline in sexuality in both genders (Edmans, 2010:188; Ross & Deverell, 2010:159; Thompson & Ryan, 2009:1807). Various reasons for this decline have been put forward, including physical changes in the brain that reduce the sexual urge, physical changes that make it difficult for the body to move, physical limitations that influence body positioning and movement during sex. Other physical changes such as incontinence, drooling, and emotional liability may be off-putting to partners. Psychological impairments and depression may affect the will to engage in sexual relationships.

Another social response to the condition of chronic illness lies in society's stigmatisation, or devaluing of the disabled person, who is unable to meet the society's expectation of functioning. Penn (in Ross & Deverell, 2010:161) explains that patients with aphasia are unable to maintain relationships and they experience functional difficulty conveying needs, communicating feelings and participating in social activities (Ross & Deverell, 2010:161).

Having noted the social consequences of stroke on patients, it is imperative to acknowledge the importance of social support in helping with the recovery

© University of Pretoria

process. As noted by Engstrom (2012:166), social support and networks have the power to strengthen health and also to buffer stress in life transition. This is confirmed in a study conducted by Hilari, Northcott and Roy (2010) on psychological distress after stroke. They discovered that low satisfaction with one's social network contributes to long-term psychological distress. Support becomes more significant to the individuals when they are at a more advanced stage of adapting to their life post stroke.

2.10.4 Economic aspects

In addition to the social consequences of stroke, patients also experience financial problems. The majority are unable to work post stroke and this creates financial burden. Economic costs related to medical treatment, rehabilitation and travelling can create enormous burdens on the patient and their family (Ross & Deverell, 2010:162). Eisenberg and Rashbaum (2011:564) confirm that it is also difficult for stroke patients to return back to work or to get reasonable accommodation in their previous employment. Stroke survivors returning to work range from 19% to 73%. Those who have returned to work have shown higher-rated subjective levels of well-being and life satisfaction, yet 75% of patients do not resume their work role post stroke. The various barriers to returning to work after stroke include hemiplegia, lack of transportation and stereotypes against persons with disabilities. This places a financial burden on the family and the government, as the majority have to apply for disability grants.

2.10.5 Religious, spiritual and cultural aspects

Chronic illness such as stroke may cause patients to deal with issues of a spiritual, religious and cultural nature. Patients' reaction to illness is influenced by the meaning they attach to the illness and their belief about the causation. Patients may raise questions about the meaning of life and may frequently use spiritual belief and practices as a way to cope with their situation (Wolfer, 2012:277). Religion and culture might not only influence belief regarding causation, but are also likely to determine whether a patient consults western health care professionals or alternative care. For example, patients who attribute the cause of stroke to ancestral spirits or to an angry God might choose to use alternative

© University of Pretoria

treatment rather than western treatment (Ross & Deverell, 2010:35). On a positive note, Hepworth et al. (2013:226) argue that spirituality can provide strength during times of adversity and the link to a faith community can be a source of support for patients.

Cultural values and attitudes may also devalue any form of dependency. From a cultural perspective, emotional reactions may be viewed as weakness of character. This further stigmatises the individual and leads to the patient avoiding acknowledging their feelings about being treated. Assuming the sick role, which demands that one adjust to the role of a patient and then relinquish that role to resume independence, may be determined culturally (Falk Kessler, 2011, 52–56).

Undoubtedly, the experiences of stroke as reported by different authors reflects that stroke alters the physical, emotional, social, economic and spiritual aspects of a patient, hence the current research focusses on all these aspects.

2.11 Holistic effects of a stroke on the family and the primary caregiver

Stroke does not only affect the individual patient, but concerns and disturbs the whole family, especially the primary caregiver. In 1917, Mary Richmond introduced the family as a treatment unit and clarified the family as a social system (Hepworth et al, 2013: 236). Therefore, as part of the system, the family will also be affected as the life of a stroke patient will intrude to the lives of everyone concerned. In addition, Ross and Deverell (2010:18) assert that chronic illnesses such as a stroke can place intolerable strain on the family because of the need for high levels of physical care and support, the emotional connotation of giving and receiving help, and changes in family roles and relationships. This is supported by Eldred and Sykes (2008:563) who indicated that most stroke survivors are cared for at home by family members – either their partners or children. They believe that the chronic burden of meeting these needs can have a significant impact on the psychological well-being of the carer.

Although family members play a vital role in meeting the physical, social and emotional needs of a stroke patient, at times there might be incongruence between the family's expectations and the patient's expectations and this might lead to family dysfunctions. Ross and Deverell (2010:160) indicate that families

© University of Pretoria

might have unrealistic expectations about the impact and the prognosis of the disease. Many families are poorly informed about the handicap and this may result in unrealistic demands from the patient. Confirmation of this is found in a study conducted by Palmer and Glass (2003), where stroke carers reported that they had not been adequately prepared for their caring role or assessed properly in terms of their ability to manage, given their skill level, age and health status (Thompson & Ryan, 2009:1804). It is against this background that Inniss (2011:625) suggests that social work intervention should help families to adjust and live with the demands of the illness and assist in navigating the health care systems.

Harwood et al. (2011:301) explain that looking after a stroke patient has physical, psychological and social consequences for the carer. He found that three quarters of carers fell ill while carrying out for their role. They report emotional distress, difficulty in problem solving, anxiety, depression and tiredness. He described different types of stress amongst carers, including identity issues (where carers either change from being a child or spouse into a caregiver), self-esteem being damaged as a result of taking on a caring role, as well as bereavement issues (where individuals grieve for the loss of the person as they were prior to the stroke).

Falk-Kessler (2011:58) indicates that the emotional reaction of the primary caregiver may result from a feeling of confinement and being overwhelmed with responsibilities, having decreased energy, lack of sleep, the sudden change in how one's family functions, change in personal plans, the overall experience of loss and even an unrealistic expectation caregivers have of what to expect. The caregiver is at higher risk due to diminished social interaction with friends. Taking on the role of a caregiver has emotional consequences. Emotional health for the caregiver will impact the patient's functional outcome.

Ross and Deverell (2010:159) highlight a number of further problems that will affect stroke patients and their caregivers. Some of these include not having quality time alone, financial difficulties, increasing social isolation of the family, sexual problems and loss of intimate relationships.

© University of Pretoria

The conclusion drawn from a study conducted on the subjective experience of caregivers in Johannesburg confirmed all of the abovementioned experiences. This study revealed difficulties in various spheres of the carer's life, such as emotional distress, assuming new roles, altered social life, sleep disturbances, relationship disruptions and health problems (Thomas, 2008:34–38). Another study focussing on these experiences was done by Anderson (1992), who found that stroke carers often have to deal with a wide range of care needs, including mobility, self-care, depression, communication difficulties and cognitive impairment in the stroke patient. These demands lead to carer burden which includes financial loss and time spent in the carer role. Common symptoms of carer burden include depression, anxiety, a decline in quality of life, social isolation, physical health problems and self-administration of medication (Eldred & Sykes, 2008:564).

Experiences of the relationships within the family system post stroke elicit a diverse range of responses; hence, the literature has contradictory results in this issue. McCarthy et al. (2011:145) have recorded positive outcomes of stroke. In their studies, there were families who described how stroke has brought them closer together, caused them to have a greater appreciation for certain aspects of their lives, and acted as a catalyst for the development of emotional strength. Contradictory to that, Thompson and Ryan (2009) found that families considered the period post stroke to be one of great adjustments, where families became less supportive.

However, there seems to be more similarities than differences in the experiences of stroke. Participants in all the studies acknowledge that stroke does not affect physical aspects only, but all areas of a person's life. It results in psychosocial changes and stresses for the patients and caregivers. All these studies found that few studies focussed on reducing the pressures families are confronted with; hence, Harwood et al. (2011:301) suggest that there is a need to educate and support carers in their role, as they are often unprepared and overwhelmed by the demands. Support for carers is necessary to sustain their health and to sustain support for the patient.

© University of Pretoria

2.12 Social work intervention with stroke patients and their caregivers from an ecological perspective

According to Gitterman and Germain (2008:72) the purpose of the ecosystems perspective is to improve the level of fit between people and their environments, especially between human needs and environmental resources. Coincidently, the focus upon the interrelationship between people and their environments has been a distinctive feature of social work since it emerged in the late nineteenth century (Donoqhue & Maidment, 2005:32). Therefore, social work intervention is required in order to improve the level of fit between stroke patients and their environments.

2.12.1 Social work intervention

According to the ecological perspective, the purpose of the social worker is to eliminate life stressors and the associated stress by helping stroke patients and their carers to mobilise and draw on personal and environmental resources for effective coping. It is also to influence social and physical environmental forces to be responsive to people's needs (Gitterman & Germain, 2008:72).

In the ecological perspective, (Gitterman & Germain, 2008:4) describe that life transitions, traumatic life events, environmental pressures and dysfunctional communication and relationship patterns can act as sources of stress for any person. It is unfortunate that, as the literature has highlighted, stroke patients have the additional burden of dealing simultaneously with physiological changes, social life transitions and traumatic life events. Using the ecological perspective, the purpose of social work is to improve the level of fit between stroke patients and their environment by enhancing their capacities and manipulating the environment so that transaction will encourage growth.

2.12.1.1 Intervention during the phases of a stroke

Social workers use a variety of interventions and provide a range of services, tasks and skills to meet the needs of stroke patients and their families at different phases of the stroke continuum.

- **Acute phase/crisis phase**

Rolland (2012:322) asserts that the crisis phase includes a readjustment period after a diagnosis and initial treatment planning. The social worker assumes multiple roles within the team, patient, family and outside resources.

© University of Pretoria

A condition such as stroke leads to functional impairments. Therefore, it causes stress and trauma to the individual and the family. When such crisis occurs, individuals are likely to use defences such as denial, anxiety and projection (Ross & Deverall, 2010:163). The social worker as a counsellor has a crucial role in supporting stroke patients to deal with their grieving process and to pull together to cope with the immediate crisis (Rolland, 2012:323). Social workers provide emotional support, encouragement to patients and their families, and they can also assist them to adjust to the illness and treatment procedures. Other responses that need counselling include poor coping and poor motivation. Therapy can be done through individual, family and group therapy (Browne, 2012:480).

As an enabler, the social worker mobilises or strengthens stroke patients and caregivers to learn to cope with sudden changes, such as sudden paralysis. In this role, Zastrow (2010:71) suggests that a social worker must encourage stroke patients and their caregivers to express their feelings about their conditions and be encouraged to perform tasks that will enhance their independence.

Browne (2012:25) points out that the social worker's teacher role is aimed at giving patients and their caregiver's information about their illness and treatment, and clarifying unrealistic expectations. Assisting patients to create meaning for the illness and maximising a sense of mastery and competency, are also functions of the social worker.

- **Rehabilitation**

Ross and Deverell, (2010:162) assert that the social worker's role during rehabilitation is to help patients deal with emotional reaction to their diagnosis, to return as soon as possible to normal activities such as work, hobbies, family and marital life, and to adopt a healthier lifestyle. As an enabler, the worker aims to help individuals and their families to discover their own strength. This role aims to empower clients (Zastrow, 2010:71). According to Ross and Deverell, (2010:163), programmes may include assisting patients to eat a low fat diet, control their weight, and learn to manage stress and anger, as well as to adhere to prescribed medical regimes. Browne (2012:482) elucidates that as enablers, social workers can encourage patients to be as active as possible with social activities and

© University of Pretoria

exercises. He further states that social workers can educate patients and their families about various rehabilitation options such as vocational and social rehabilitation. The social worker must also advise them about financial issues and social security benefits (Ross & Deverell, 2010:163). The social worker must also advocate for stroke patients within the health care system, as well as with community agencies (Hepworth et al., 2013:30). Social workers must facilitate support groups for stroke patients and their families. They must also be encouraged to join a support group and attend health education activities (Rolland, 2010: 326).

- **Discharge**

Harwood et al. (2011:185) indicate that social workers need to be involved in discharge planning. They need to prepare the family for discharge and facilitate participation of caregivers in the movement of stroke patients from a medical setting to the home or other residential place. Both the patient and the other family members need to be involved and prepared for the transition. As a broker and advocate, the worker must connect the patient and the caregiver with home-based care support such as NGOs, day-care centres and volunteers

- **Community-based rehabilitation**

Edmans (2010:174) acknowledges that taking rehabilitation to the community is an important component to the continuum of care of stroke patients. He points out that community rehabilitation is an umbrella title for a number of stroke services in the community, mostly administered in people's own homes, but which can take place in community centres, health centres, care homes and stroke clubs. As part of the multidisciplinary teams, the social worker assists with the reintegration of stroke patients into the community and provides a wide range of therapy which includes leisure rehabilitation, community skills, self and home management. On-going psycho-social support and awareness-raising is also crucial at the community level.

2.13 Summary

The literature has described quite well the characteristics of people who suffer strokes, the treatment regimens available to them and ways in which they depend

© University of Pretoria

on others. It has also shown that stroke is a brain disease that affects physical function and consequently alters the emotional, social, spiritual and financial well-being of both the patient and the carer. Given the statistics and the prevalence of stroke, it is not surprising that it has been cited as the second leading cause of disability after HIV/AIDS globally. It appears that treatments for stroke are advanced and effective, resulting in a high number of people surviving stroke and being cared for at home. This chapter has tried to show other path of prior literature and to compare similarities and differences.

It has also traced the evolution and development of the ecological systems tradition. It identified a number of key theoretical concepts that provide a foundation of the ecological approach. From where it evolved as systems theory to the ecosystem perspective, the central theme has been the importance of the interaction and interdependence of the person and their environment. To understand the aftermath of stroke, this chapter outlined the multiple factors that contribute negatively or positively to the well-being of patients and their caregivers. Multi-levelled systems that may prevent or effect change were identified. It is evident that to deal effectively with the aftermath of stroke, assessment and interventions should occur at the micro, meso, exo and macro level.

In conclusion, although stroke has devastating effects, as mentioned above, it does not have to mean the end of the emotional and social health of patients and carers. The social worker, because of their commitment to viewing people within their social context, can intervene at all levels to reduce the burden of stroke among patients and carers.

The next chapter will focus on the research methodology and findings.

© University of Pretoria

3. CHAPTER THREE: RESEARCH METHODOLOGY, EMPIRICAL STUDY AND RESEARCH FINDINGS

3.1 Introduction

This chapter presents the research methods used and the various research processes followed. The recruitment of participants and the data collection processes is explained and the data analysis process is provided. Ethical considerations made in this study are also discussed. The research findings are presented, starting with demographic information and followed by recurring themes. Finally, a summary is provided.

3.2 Research approach

As the researcher wanted to explore the experiences of patients and caregivers in the aftermath of stroke, the qualitative approach was identified as the best approach to address this goal (Fouché & Delport, 2011:64). The researcher used exploratory research to understand the social life and meaning that stroke patients and caregivers attach to their everyday life (Fouché & Schurink, 2011:308). The nature of this study was highly sensitive as it tapped into the daily living of stroke patients and their caregivers; hence, the use of the qualitative approach encouraged a holistic approach and facilitated a clearer understanding of the phenomenon (Fouché & Delport, 2011:65).

3.3 Type of research

The aftermath of stroke was probed from both the patient's and the caregiver's point of view. This assisted the researcher to make recommendations for appropriate intervention strategies, implying applied research. This research was not aimed at developing new knowledge, but merely at addressing a specific concern or exploring and offering recommendations for dealing with the aftermath of stroke. It was thus of an exploratory nature (Neuman, 2006:25). Applied research, in this context, was used to do scientific planning of induced change in the troublesome situation of people dealing with the aftermath of stroke (Fouché & De Vos, 2011:94).

© University of Pretoria

3.4 Research design

The case study design was used in this study as it offers multi-perspective analysis in which the researcher could consider not just the voice and perspective of one or two participants, but also the views of other relevant groups and the interaction between them (Nieuwenhuis, 2010a:75). A case study must be a bounded system (Kumar, 2011:126) and it is defined as a systematic enquiry into an event or set of related events which aims to describe and explain a phenomenon such as the aftermath of stroke on patients and their caregivers (Nieuwenhuis, 2010a:75).

The collective case study design was considered relevant in this study because the researcher wanted to gain a holistic understanding of how stroke patients and caregivers experience the aftermath of stroke and how they interact with each other to deal with the effects of stroke (Fouché & Schurink, 2011:320). The utilisation of the collective case study design created an opportunity for the researcher to gain a comprehensive and deeper understanding of the aftermath of stroke on the patient and the caregiver (Nieuwenhuis, 2010a:76). The disadvantage is that it is incapable of providing a generalised conclusion. However, this study aimed to provide a comprehensive view of the effects of stroke on the patients and the caregivers, acknowledging the influence the South African context has on these experiences.

3.5 Research methods

3.5.1 Study population and sampling

3.5.1.1 Study population

To explore the aftermath of stroke from all patients who possessed the same attribute was impractical; hence, instead of interviewing all potential participants, the researcher drew a sample from the population (Strydom, 2011a:223). The first population in this study were ischemic and haemorrhagic stroke patients who received treatment and therapy at KT Motubatse and Clinic 3 in Soshanguve and the second population were the caregivers who resided with the chosen patients. These populations helped to set boundaries on the study units and they exhibited certain characteristics (Strydom, 2011a:223). KT Motubatse clinic and Clinic 3 were specifically chosen because they are the biggest CHCs in Soshanguve which run support groups for stroke patients.

© University of Pretoria

To select a subset of the population, a non-probability sampling method was used for both the patient and the caregiver because the researcher was not interested in the representativeness of the sample, but rather in cases that could clarify and deepen understanding (Neuman, 2006:220). One of this method's strengths is that it usually involves small sample sizes, which makes it flexible, and data is collected until no new themes emerge (that is, when the information being gathered becomes repetitive) (Maree: 2007:7).

The researcher used purposive or judgement sampling in this study as it involves the researcher using her own judgement to choose participants who can provide the best information to achieve the goal of the study (Kumar, 2011:207). This method is used in special situations where the sampling is done with a specific purpose in mind. This involves the researcher choosing a specific case on the grounds that it illustrates features, as set out below, which are of interest for the particular study (Strydom & Delport, 2011:392). In this study, the researcher first sought permission from the clinic managers and from the health district research committee to interview stroke patients and their caregivers. Written consent was granted. The rehabilitation team in both clinics runs open therapy groups every week for stroke patients. Stroke patients who met the inclusion criteria were recruited during the support groups at KT Motubatse clinic and Clinic 3. The inclusion criteria were explained to the group and stroke patients who met the criteria volunteered to participate. Verbal and written consent was gained. The following selection criteria were utilised:

- Patients must have been diagnosed with either irreversible ischemic or haemorrhagic stroke (CVA).
- A six-month post-stroke adaptation period must have taken place. This allowed a sufficient period for psychosocial effects associated with stroke to be experienced.
- Patients with severe communication problems such as aphasia, dementia and dysphasia were excluded.
- Any persons above 18 years of both genders were included.

© University of Pretoria

- The stroke survivor had to be residing with a caregiver.
- Patients needed to speak and understand either English or Sesotho.
- The stroke patient had to be available and willing to participate in the study.

Caregivers who met the following criteria were purposively selected for the research study:

- The caregiver had to reside within the same residence as the stroke patient.
- The study should comprise caregivers of both genders who are aged above 18 years.
- Caregivers needed be available and willing to participate.
- Caregivers needed to speak and understand either Sesotho or English.

The patients who volunteered to participate approached their caregiver and informed them of the study. The researcher then approached the caregivers who came with the stroke patients to the support group and read the letter of informed consent to them, after which they signed and agreed to participate voluntarily. Those caregivers who could not come with patients to the group gave their contact details via the patient and were contacted for appointments at which the letters of informed consent were read through with them and their verbal and written consent to participation in the study was obtained. The interviews were conducted in the clinics or in the homes of the stroke patients.

3.5.2 Data collection

Semi-structured, one-to-one interviews were conducted as a method to elicit information from stroke patients and their caregivers. Interviews are predominately used as data collection instruments in qualitative research because they enable the researcher to understand the world from the participant's point of view and to unfold the meaning of people's experiences (Greeff, 2011:342).

© University of Pretoria

Although semi-structured interviews were used with an interview schedule, the participants had more control over the agenda as they were able to raise their concerns and priorities, rather than the agenda being dictated by the researcher (Greeff, 2011:352). Two different interview schedules were used – one for the patient and another for the caregiver. The interview schedule for the patient focussed on the experiences of stroke patients, exploring the following themes: warning signs, physical aspects, financial problems, relationship problems, emotional problems and altered social life.

The interview schedule for the caregivers explored the following themes: aspects of distress, their views of the impact of stroke on the patient, burden of caregiving, social support and role changes. In this study the aim of utilising a semi-structured interview was to gain as much detail as possible about the experiences participants attach to the aftermath of stroke. New ideas and interesting avenues that emerged during the pilot study were added to the interview schedule (Greeff, 2011:351). These included participants' thoughts regarding the perceived cause of their stroke.

In order to develop a rapport, the researcher engaged in some informal discussions with each interviewee before the interview began. This helped to put the interviewees at ease. Given the unpredictability of the literacy level of the participants, the researcher did not use jargon or ambiguous questions, but rather used simple, open-ended questions in order to allow participants to express themselves freely. Certain questions were asked to all participants along various themes, but some ad hoc questions were used to explore various answers. The researcher compiled the interview schedule, which consisted of a few relevant themes (Greeff, 2011:352). The duration of the interviews with stroke survivors was tailored to their ability in order to avoid physical exhaustion, with the shortest interview taking 25 minutes and the longest lasting 45 minutes. Interviews were held separately for both the patients and their caregivers. The number of participants was determined by the number of interviews that it took to reach saturation. In this study, after ten interviews the recruitment of participants stopped, as a point of saturation was reached. All the interviews were conducted in Sesotho and permission was obtained from the patients and the caregivers for the interview to be audio-recorded and transcribed.

© University of Pretoria

3.5.3 Data analysis

The data was analysed following the interpretive philosophy. The interpretive philosophy is aimed at examining meaningful content (Nieuwenhuis, 2010b:99). It tries to establish how participants make meaning of specific phenomena. In this study the aim was to analyse the perceptions, feelings and experiences of stroke patients and their caregivers; hence, a thematic analysis was utilised. Data was translated into English and backward translation was conducted by the researcher to align the original meaning posed by participants. The researcher followed the process of data analysis proposed by Creswell (2007), as cited in Schurink, Fouché and De Vos, (2011:403). The steps were not followed rigidly, but were used as a guideline.

3.5.3.1 Planning for recording data

Interviews were held in the clinic or in the participant's home. All interviews were recorded after permission to do so was obtained from participants.

3.5.3.2 Data collection and preliminary analysis

When the data collection process reached the point of saturation, the process of data analysis began. The process of analysis was twofold. The first part was on-going and it started with the interviews. Each time a new interview was transcribed, the others were re-read in order to enable the researcher to become familiar with the data. The second part involved analysis away from the field, following a period of data collection. The office-approach analysis included sorting of interview transcripts and field notes and listening to audio recordings. The audio-recorded interviews were transcribed word for word into written text.

3.5.3.3 Managing data

In order not to become overwhelmed with the amount of data, the researcher organised and kept track of the text. The researcher transcribed all audio-recorded interview material after each interview to ensure that everything was captured correctly. The audio recordings were done with the researcher's phone to ensure

© University of Pretoria

safety, and transcripts were kept in a lockable drawer. The transcripts, memos and field notes were marked with the date, time and place. The researcher used folders, files and boxes to gather together material dealing with the same data. Sets of data in the folders were labelled using pseudonyms to protect the identity of participants (Nieuwenhuis, 2010b:104).

3.5.3.4 Reading and writing memos

Handwritten notes were made immediately following an interview. The researcher then listened to the interviews to gain understanding in context and to familiarise herself with the content. Interview transcripts were read and reread several times to achieve comprehension (Schurink et al., 2011:409). Field notes and thoughts were added in side columns of transcripts.

3.5.3.5 Generating categories, themes and patterns

The researcher analysed data by organising it into categories on the basis of themes, concepts and similar features. The researcher grouped similar themes together. Themes that were recurring were identified and grouped together. Data collected from stroke patient was organised separately from data collected from caregivers. Although the uniqueness of each participant's experience is acknowledged, there were shared experiences that formed themes. These recurring themes were grouped into categories according to their similarities and differences (Neuman, 2006:460). Each category was assigned a name until no new themes emerged.

3.5.3.6 Testing the emergent understanding

During interpretation of data, the researcher evaluated the available data by re-examining themes that emerged and searched for patterns.

3.5.3.7 Interpreting and developing topologies

Interpretation involved searching for lessons learned from the collected data. The researcher formed a broader opinion of what was going on with the data. Developing systems for categorising things or concepts was useful in making

© University of Pretoria

sense of the collected data (Schurink et al., 2011:216). The collected data was interpreted according to an ecological perspective as a theoretical framework.

3.5.3.8 Presenting data

In the final phase the researcher packaged what was found from the collected data in a written research report. Finally, the data was presented in narrative, tabular or figure form.

3.5.3.9 Trustworthiness

To ensure the trustworthiness of the study the researcher followed the criteria developed by Lincoln and Guba (1999), as cited in Schurink et al. (2011:419), which considers the credibility, transferability, conformability and dependability.

Credibility: “involves establishing that the results are credible or believable from the perspective of the participant in the research” (Trochom & Donnelly, 2007 in Kumar, 2011: 185). The goal of credibility is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described. To ensure credibility, the researcher kept an audit trail throughout the process of data analysis that clearly described the steps followed. The researcher was guided by her university supervisor, who facilitated the research objectively and independently verified the interpretation of data. Member checking was done, whereby the researcher conducted another interview with participants after data analysis, to ensure the data had been interpreted correctly, thus ensuring trustworthiness.

Transferability: refers to the degree to which the results can be generalised or transferred to other contexts or settings. Although it is difficult to establish transferability, it can be achieved through extensive and thorough description of the process for others to replicate and follow (Trochom & Donnely, 2007 in Kumar, 2011:185). In order to achieve transferability, the researcher provided an accurate description of the research methodology employed at each step along the way.

© University of Pretoria

3.6 Pilot study

To pilot-test the interview schedule for the patient and caregiver, interviews were conducted with two stroke patients and two caregivers from Maria Rantho Clinic in Soshanguve, in the north of Tshwane district. The pilot study was used as a dress rehearsal where the researcher determined the appropriateness of the selected research design, semi-structured interview and interview schedule. Participants and the data collected from the pilot study were not included in the main study, but it assisted in identifying gaps prior to the main study (Strydom, 2011b:237).

3.7 Ethical considerations

As a registered social worker, the researcher adhered to high ethical standards to protect the stroke patients and their caregivers and to reflect the professionalism of the social science discipline. Ethics implies preferences that influence human behaviour in human relations, conforming to a code of principles, the rules of conduct, the responsibility of the researcher and the standards of conduct of a given profession (Babbie, 2007 in Strydom, 2011c:114). Ethical clearance was obtained from the Ethics Committee of the University of Pretoria and from the National Department of Health. The most important ethical issues that the researcher considered include the following:

3.7.1 Avoidance of harm

The researcher acknowledges that the topic under study forced participants to face aspects of their situation that they might have been ignoring (Babbie, 2008:68); hence, the interviews were a bit emotional. The researcher took measures to minimise the emotional harm by ensuring that interview schedules were properly planned and the wording was not too sensitive. Ethical approval was sought from the Ethics Committees of the Faculty of Humanities at the University of Pretoria and from the National Department of Health. Participants were informed beforehand about the nature of the study and the right to withdraw from the study if they felt uncomfortable; however, at no point during an interview did any of the participants refuse to answer questions. The researcher also checked on how the interviewee was feeling after the interview. Two participants who were a bit emotional were offered an opportunity to consult with an

© University of Pretoria

independent social worker at Maria Rantho Clinic. The clinic had been informed prior to the commencement of the study about the possibility of referrals.

3.7.2 Informed consent

The researcher obtained verbal and written informed consent from participants before the interviews were conducted and they were informed about the voluntary nature of participation. The researcher ensured that participants were not coerced into signing by giving them a brief description of the purpose and procedure, as well as a statement of any risks (Neuman, 2006:129,136). During the recruitment period, adequate information about the research was provided to the potential participants to ensure understanding and to allow them to decide for or against participation. Informed consent letters were read through with each participant and they were provided with all the information pertaining to the research. All participants expressed their willingness to voluntarily participate in the research. The researcher ensured that all participants (patients) were in a sound state of mind before they signed the consent forms, hence exclusion of patients with dementia and dysphasia. The right to withdraw from the study at any time was made clear to participants at the onset. The researcher obtained permission from the participants to use an audio recorder and informed them that the data would be transcribed and stored for 15 years at the University of Pretoria.

3.7.3 Deception of subjects

The purpose of the research was highlighted and the participants were not given any false information or unwarranted reassurance. The researcher shared and did not conceal that she is conducting research for a master's degree and accurate information about what the research intended to achieve was highlighted (Babbie, 2008:72). The researcher checked with the members about their understanding of the research processes to ensure that they had no unrealistic expectations. There were no false expectations in this study.

© University of Pretoria

3.7.4 Violation of privacy/anonymity/confidentiality

Information was collected from participants by the researcher, but respondents were given fictitious names so that their identity is protected (Babbie 2008:69). The information provided by the participants was treated confidentially and they were assured that only the researcher and her supervisor will have access to their full transcripts. Field notes, reports, transcripts and audio recordings did not contain the names of individuals, as pseudonyms were used. Information that might identify the participants, such as their address, would not be used in the research report. Using experts and editors is considered less exposing as no identifying particulars will be in the report. The recordings and the transcripts were kept in a lockable drawer and information received was only used for research purposes.

3.7.5 Action and competence of the researcher

The researcher abided by the professional standards and ethical expectations of social work throughout the study. The researcher is also conversant with the research processes as she has passed the postgraduate research methodology module. All the researcher's interviewing skills were utilised and participants were treated with respect and as unique individuals. The researcher honoured appointments made with clients and arrived on time. The researcher refrained from value judgements about the views of participants (Strydom, 2011:123,124). The study was conducted under the supervision of a supervisor from the University of Pretoria.

3.7.6 Debriefing of subjects

After the interviews, the trustworthiness of the qualitative data was checked through reflection and debriefing of participants. The researcher discussed the experience of the research process with the participants to ensure that there were no unintended or unanticipated effects of the research. Babbie (2001), as cited in Strydom (2011c:122), asserts that this is the period where misconceptions and problems created during the research can be corrected. Debriefing was a way in

© University of Pretoria

which both the researcher and the participant learned from the experience (Strydom, 2011c:122,126).

3.7.7 Publications of findings

After completion of the study, the researcher compiled a report which is accurate and objective. The research report is written in plain, simple language and it gives accurate findings. Limitations of the study are highlighted in the report. The researcher did not deceive the reading public by manipulating the results or giving false findings. The researcher engaged the supervisor and other experts to ensure that the qualitative data was accurately analysed. The findings will be revealed to subjects in an objective manner without too many details or impairing the principle of confidentiality (Strydom, 2011c:126). Sources used in the report were acknowledged.

3.8 Empirical findings of the study

In this section, the results of the study are presented. It begins with the demographical profile of participants, followed by a discussion of the themes and sub-themes that emerged with both the stroke patients and their caregivers. Five stroke patients and five caregivers were interviewed. Themes that emerged from stroke patients and caregivers are combined and discussed together, and similarities and differences are discussed where necessary. Quotes from the interviews are used to support the themes. Data will be presented in a narrative, tabular or figure form and theory is integrated throughout the discussions to support the research findings.

3.8.1 Biographic profile of participants

The profiles of the participants are summarised in the table below. Information obtained includes age, gender, marital status, employment status and time since the onset of stroke. Worthy of note is the fact that all participants were black and this was mainly due to the fact that residents of Soshanguve are predominantly black and thus there were no coloured, Indian and white participants.

© University of Pretoria

Table 3.1: Identifying details of participants (patients and caregivers)

Age	Gender	Marital status	Employment	Time since stroke	Relationship
Patient: 73 Caregiver: 24	Male Male	Widow Single	Pensioner Unemployed	Seven months	Grandfather Grandson
Patient: 76 Caregiver: 65	Male Female	Married Married	Pensioner Pensioner	Seven months	Husband Wife
Patient: 69 Caregiver: 50	Male Female	Married Married	Pensioner Employed	Four years	Husband Wife
Patient: 57 Caregiver: 53	Male Female	Widow Single	Unemployed Employed	Seven years	Boyfriend Girlfriend
Patient: 52 Caregiver: 29	Female Male	Widow Single	Unemployed Employed	Four years	Mother Son

The table presents the data pertaining to each patient and their caregiver in one row. Each of the variables will be discussed below.

3.8.1.1 Age

All the participants who took part were over 18 years, as per inclusion criteria. The risk of stroke increases with age (Bryer et al., 2010:754), and therefore it is not surprising that the majority (3) of the patient participants shown in table 3.1 are older than sixty five years (aged 76, 73 and 69 years respectively) and only two participants were younger (52 and 57 years). This is consistent with various literature studies that acknowledge that with an increase in the age of a given sample population, especially after 55 years, the incidence of stroke is predicted to rise due to increased incidence of stroke associated with age (Wasserman et al., 2009; Eisenburg & Rashbaum, 2011:55). A high proportion (3) of caregivers are over 50. They are aged 65, 53 and 50. Few (two) are in their twenties, aged twenty-nine and twenty-four respectively.

© University of Pretoria

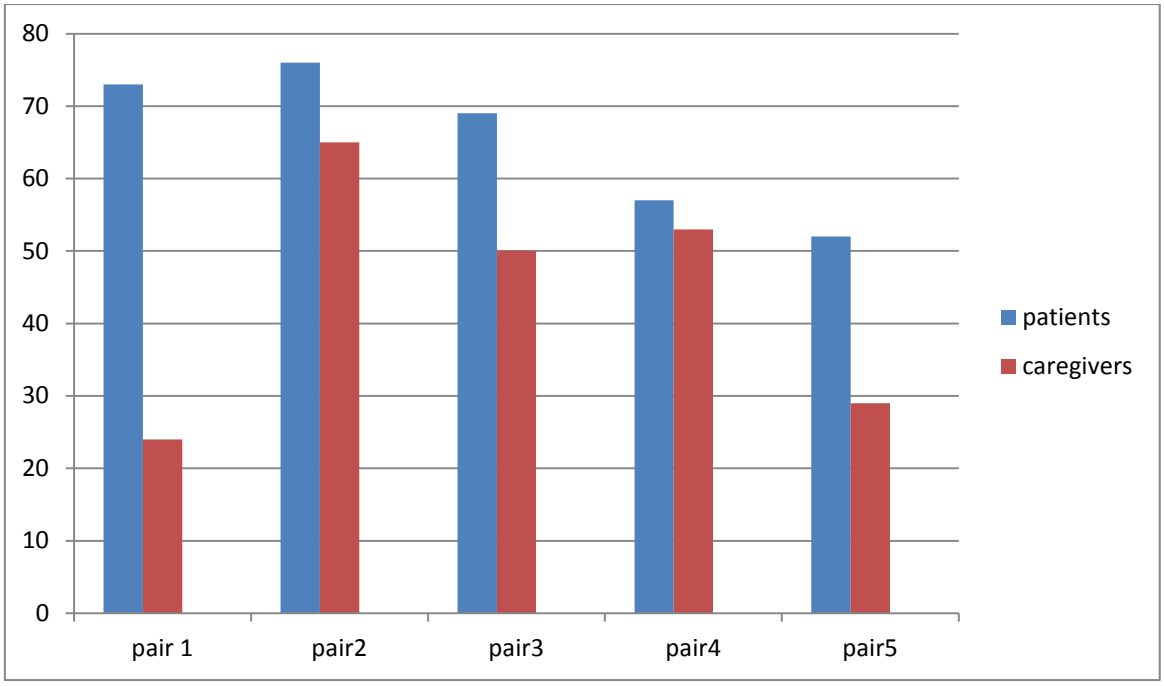


Figure 3.1: Age of patients and caregivers (N=10)

3.8.1.2 Gender

According to the American Heart Association (2010), at older ages there is no gender difference in incidence of stroke; nonetheless, more women than men die yearly of stroke. In the same vein, Bryer et al. (2010:754) indicate that black women in South Africa have the highest mortality rate owing to stroke (160 per 100 000). In this study, most participants who met the inclusion criteria were men (4) with only one woman, which could be due to the fact that more male patients survive. The age and sex of caregivers were related. The majority (3) of older caregivers were females, whereas only a few (2) were young males. Most (4) caregivers were caring for a patient of the opposite sex and one grandson cared for his grandfather. Although Falk-Kessler (2011:58) contends that the burden of stroke falls on women, Rolland (2012:336) argues that an illness such as stroke, provides an opportunity to encourage flexibility and a shift from defining females as the caregivers to a collaborative team that includes males and females, children and spouses as is illustrated in this study.

© University of Pretoria

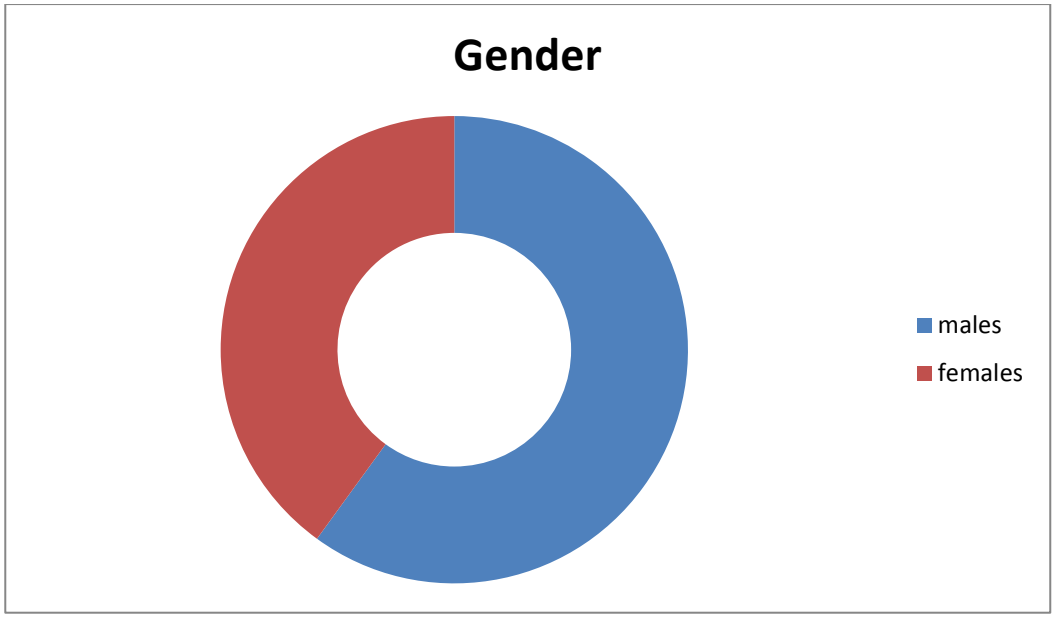


Figure 3.2: Gender of participants (N=10)

3.8.1.3 Marital status

Marital status and social support are mentioned as psychosocial risk factors related to cardiovascular diseases by Ross and Deverell (2010:156). According to their stance, people who have no partners or who lack the social support of a confidant are at risk of developing cardiovascular diseases. In this study, (3) participants were widows or widowers and only (2) were still married. Three of the caregivers were single while two were married.

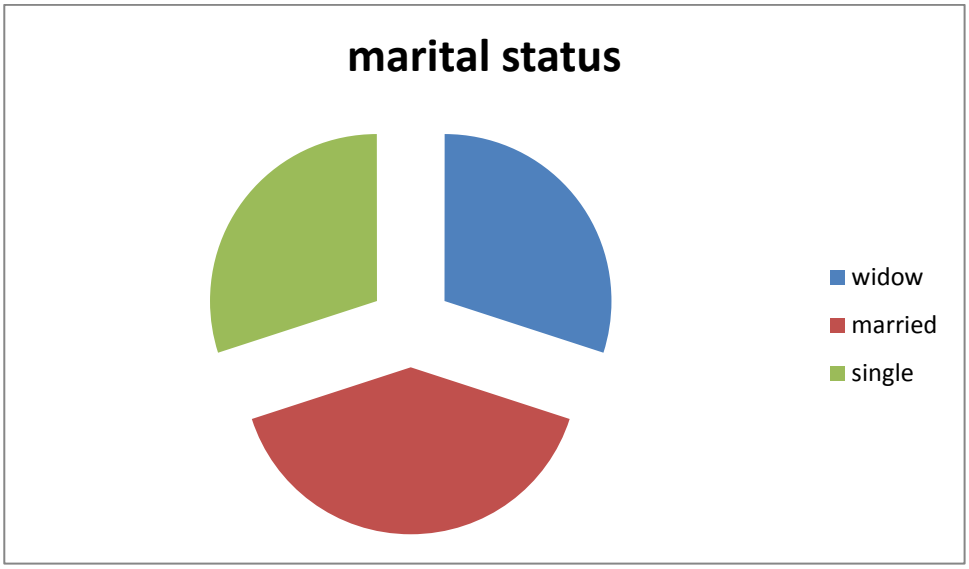


Figure 3.3: Marital status of participants (N=10)

© University of Pretoria

3.8.1.4 Employment

Figure 3.4 below summarises the employment status of stroke patients at the onset of their disease and of caregivers. Literature indicates that there is no doubt that social class has a major impact on physical health and the relationship between the two remains complex and heavily debated (Larkin, 2011:65). In this study, the relationship between the onset of stroke and economic status is considered of little significance. Participants vary from low to middle economic status. Three stroke patients were still gainfully employed when they had a stroke and the other two were already pensioners. Presently, two patients are dependent on old age grants, as their age warrants, and one is dependent on relatives as he is still sorting out his old age grant issues. Only two are unemployed and receive a disability grant as their source of income. Three (3) of the caregivers are still in paid employment. One is a pensioner and one is unemployed. As can be seen, the highest employment was amongst the caregivers.

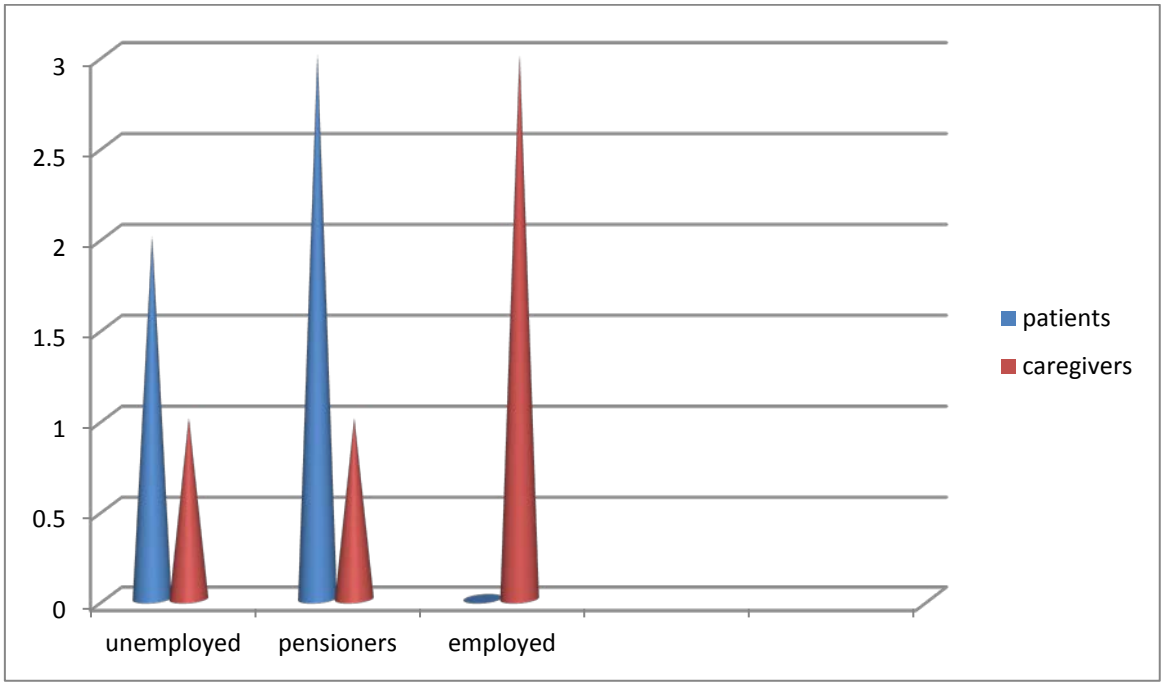


Figure 3.4: Employment status of patients and caregivers (N=10)

© University of Pretoria

3.8.1.5 Relation of caregiver to stroke patient

A caregiver is someone who looks after a partner, relative or friend because of illness, disability, frailty, or the effects of old age (Harwood et al., 2011:303). The participants in this study conform to the above definition, as the majority (3) of the caregivers were the patients' spouses, one was a son and the other a grandson. All were living with the stroke patients as per the inclusion criteria.

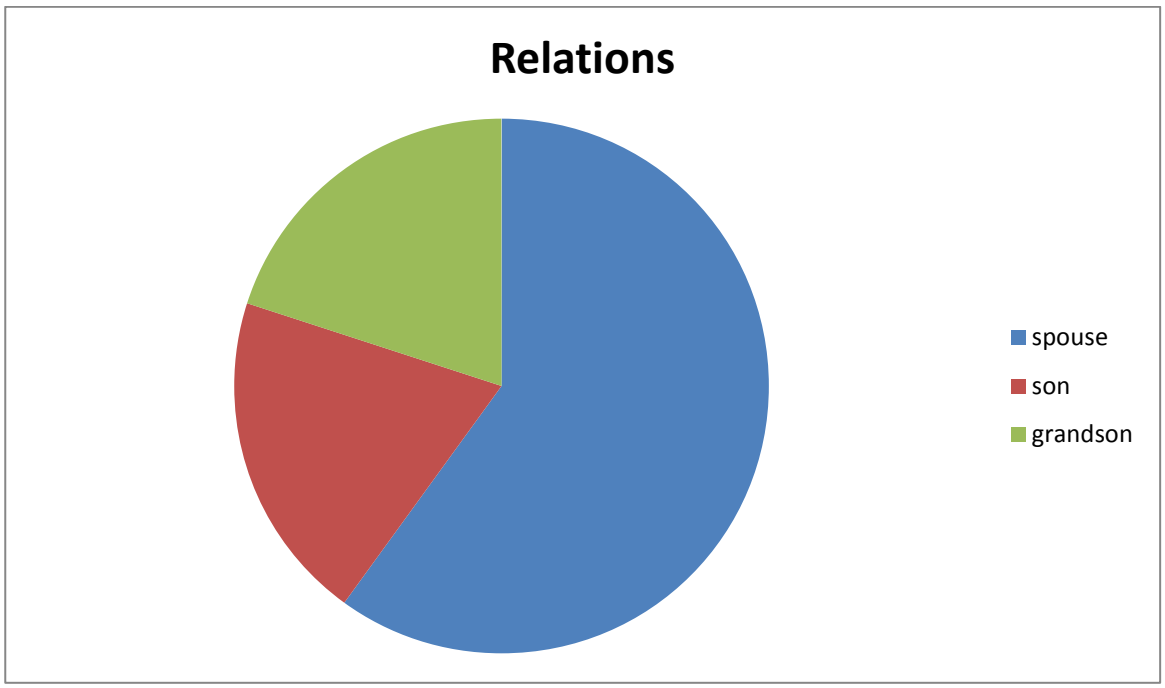


Figure 3.5: Relation of caregiver to stroke patient (N=10)

3.8.1.6 Time since onset of stroke

All patients and their caregivers had had time to reflect upon the impact of stroke, as, in all cases, more than six months had elapsed since the stroke, as per the inclusion criteria. Two had been living with the effects of stroke for seven months, two for four years, and one for seven years. Most of the caregivers (4) had been with the stroke patient since its onset and only one started residing with the stroke patient three years after the stroke.

© University of Pretoria

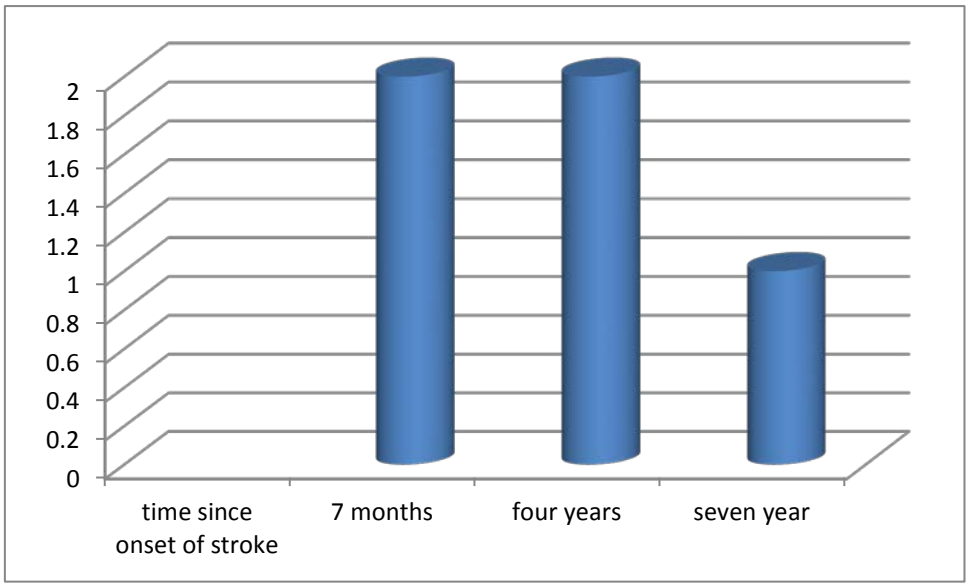


Figure 3.6: Time since onset of stroke (N=10)

3.8.1.7 Diseases before stroke

The most common long-standing illness that patients mentioned in this study was hypertension (all), followed by diabetes (3) and only one (1) had had a previous stroke and one (1) has asthma. This confirms the statement by Eisenberg and Rashbaum (2011:550) that indicates that the established greatest risk factors for stroke include age, hypertension, diabetes and a previous stroke. All patients were independent in activities of daily living before the stroke.

3.8.2 Profile of research participants

Table 3.2: Profile of research participants

Participant 1 and his caregiver	Participant 1 is a 73-year-old male who resides with his grandson, aged 24 years, in Soshanguve Block K. He had two children with his wife, but unfortunately his daughter died in 2010 and his wife followed her in 2011. His only son lives with his family in Mamelodi, so he is being cared for by his grandson. He suffered a stroke in September 2014 while he was already a pensioner. His grandson is unemployed and hence they only survive on his old age grant.
Participant 2 and his caregiver	Participant 2 is a 76-year-old male who resides with his second wife, aged 65, in Soshanguve Extention 3. He was married to two wives, but one died in 2012. He has four children with his first wife, but does not have children with his second wife. He used to work as a driver for a delivery company in Pretoria

© University of Pretoria

	West. He left this company due to an empowerment programme that was introduced in 2013. He had his stroke in September 2014, while he was still trying to sort out his issues with this company. He does not receive his old age grant as yet, but his wife does receive the old age grant. His third son is the one who meets all their financial needs
Participant 3 and his caregiver	Participant 3 is a 69-year-old male who is married to a 50-year-old woman. The couple resides in Soshanguve Extention 4, although they are originally from Venda. When the participant married his wife, she already had one son and their marriage was blessed with another son. His son resides with them inside the house, while his step-son stays with his girlfriend in the adjacent room. The patient was working as a mechanic in Centurion when he had his stroke in 2010. He has since stopped working and now receives his old age grant. His wife is employed as a cleaner in Johannesburg.
Participant 4 and his caregiver	Participant 4 is a 57-year-old male who is originally from Venda. His parents are deceased and his wife died in 2008 shortly after he had his stroke. He has a son with his deceased wife, but the son resides with his maternal relatives. Presently, he resides with a partner who is 53 years old in Soshanguve Block xx. He used to work as final car inspector in Rosslyn, before he had a stroke in 2008. He continued to work after his stroke, but his company was liquidated and he now survives on a temporary disability grant. His partner works as a domestic worker in Pretoria.
Participant 5 and her caregiver	Participant five is a 52-year-old woman whose husband is deceased and she resides with her 29-year-old son in Soshanguve Block G. Her parents are deceased, but she has two brothers who live in their own places. She used to run her own tavern but she had to close it after the stroke in 2012. She is being cared for by her son who is employed at UNISA She also receives disability grant and also receives an allowance from a brother who owns taxis.

3.8.3 Themes and sub-themes

Themes and sub-themes that emerged during the data analysis are firstly summarised in table form and discussed thereafter. Direct quotations from the participant interviews are used to support these themes, while literature is also used to substantiate the findings.

Table 3.3: Themes and sub-themes

© University of Pretoria

Themes and sub-themes	Sub-themes
Stroke onset	Warning signs Seeking medical help Treatment received Understanding of stroke
Physical consequences	Neurological impairments Functional abilities • Mobility • Communication • Self- care
Spiritual consequences	
Financial consequences	Returning to work Added financial costs
Emotional consequences	Feelings during acute phase Feelings during chronic phase Personality changes
Social consequences	Social activities Sources of support • Attitude of the community • Relationship with the family • Relationship with the primary caregiver • Sexual relationship • Attitudes of service providers
Patient's greatest loss	Views of the patients Impact according to the caregiver's view
Caregiver burden	Day-to-day tasks Health problems Aspects of distress
Coping strategies	

© University of Pretoria

Recommendations	Recommendations to stroke patients Recommendations to caregivers Recommendations to service providers

3.8.3.1 Theme 1: Stroke onset

This section focusses on how participants experienced the onset of stroke. It illustrates how participants interpreted the warning signs, how they reacted to those signs, medical attention they received and their understanding of the diagnosis.

3.8.3.1.1 Sub-theme 1.1: Warning signs

At the time of the onset of stroke the participants were at different places doing different things. The majority (3) were at home, one was at work and the other one was doing shopping. Participants were requested to describe what happened the day they had the stroke and any warning signs they experienced beforehand. They all reported that they suddenly could not do something that they usually took for granted, such as walking and talking. This is exemplified in the following quotes from some of the participants: patient 2 said:

> I went to do shopping with my wife and when we got into the parking lot, I tried to get out of the car but I felt weak and dizzy. I tried to get out of the car but I saw darkness.

His version of events was supported by his wife who added:

> I saw him being funny and his mouth was on the side. I bought him biscuits and forced him to eat as I thought it was diabetes. We drove back home but when we arrived at home he could not stop the car and he bumped into a tree. His mouth was completely on the side and he could not walk or talk.

Other responses show how caregivers and patients waited for symptoms to develop before seeking help. Patient 1 and his grandson recalled how the stroke developed:

> My second stroke was really surprising and strange. One morning I woke up and I felt that there was something heavy on my shoulder. I checked in the mirror but there was nothing. As time went on I realised that my arm was weak and my leg was shivering. My eyes became blurry. I tried to pick something up and I fell. The very same week, I fell while I was sitting on a sofa. I tried to stand up but I could not. I called my grandson to help me. He asked, “Grandfather, are you sick again?”

© University of Pretoria

> The following day we went to the clinic and when we came back I realised that my arm and leg were now paralysed. This stroke to me was very strange and a shock as I thought stroke happens fast. You might say that mine developed over time rather than happening all at once.

It appears that some of the symptoms of strokes are less dramatic, as in the following case, recounted by patient 5:

> I used to sell bunny chows and chips in my tavern. I don't understand what happened. On Fridays, Saturdays and Sundays we used to have gigs in the tavern. I used to prepare food for people who came to buy alcohol. I worked the whole weekend but on a Monday in June 2011, I called someone to go and buy things for my business. I tried to write a list of the things that needed to be bought but, to my surprise, I struggled to write. My hand could not write. I wanted to say something to the boy but no words came out. I became confused. I asked myself, "What is wrong?" But I could not explain it.

It is apparent that some of the experiences are a bit more dramatic as in the case of patient 4 who cannot recall what happened and patient 3 whose dream highlights the role of traditional beliefs. This is what they reported:

> I don't want to recall that day because it ruined my life. I am not sure what exactly happened. I always got paid every Friday and this particular Friday in 2010, I think it was June or July – I am not sure but I know it was cold. I went to party with friends after work. We drank alcohol and the next thing I woke up in hospital.

> I was working night shift and after work I went home to sleep. Unfortunately, that morning I struggled to fall asleep. After a while, maybe fifteen minutes later, I think I had a light sleep. In that sleep I saw a shadow of a person passing in front of me. That person or shadow, which I think was a witch, came back and tried to pick me up. I was strong and managed to overpower the shadow and eventually it dropped me on my bed. When I woke up, I immediately realised that my left side was weak. I could neither walk nor talk.

Steyn (2007:3) reports that stroke symptoms start suddenly, over seconds and minutes, and in most cases do not progress further. This is evident in the statements mentioned by most (4) of the participants in the above quotes. The symptoms experienced by the participants in this study bear testimony to what Edmans (2010:2) summarised as the initial symptoms of stroke. She asserts that patients will experience sudden weakness, numbness of the face, arm or leg on one side of the body, sudden loss of vision in one or both eyes, sudden difficulty speaking and dizziness or a sudden fall.

© University of Pretoria

3.8.3.1.2 Sub-theme 1.2: Seeking medical help

Following the onset of the symptoms, patients and caregivers, for various reasons, took time in seeking medical attention.

Caregiver 3 whose husband was too ill to play any role in seeking medical help, and caregiver 5both engaged in the process of interpretation of symptoms and they preferred to discuss the condition with friends and family members before seeking medical help. They recounted their experience as follows:

> The day my husband had his stroke, he went to party with friends in a shebeen after work. I was surprised when his friends brought him home around twelve midnight. They said, "We have brought your husband, he is drunk." I said, "Why have you brought my husband home? He has his own key." They laid him down and left. I thought he was drunk. In the morning I continued with my usual chores. It was around eleven in the morning that I realised he was not going to wake up. I called his friend who had brought him home. The friend came and tried to wake him but still he did not wake up. We then called an ambulance and they checked him and told me he had had a stroke. They asked me if I did not notice that he had had a stroke and I said he came home drunk so I thought he was still drunk. The ambulance took him to Dr George Mukhari Hospital (DGMH) where he was admitted. It was during the time when the nurses were on strike, hence they discharged him in less than a week.

> I was confused and observed my symptoms until my son came home. Around half past six my son came back and I tried to explain what had happened but nothing came out. He took me to a private doctor who referred me to Kalafong and they referred me to DGMH. I stayed in hospital and was discharged after four days.

Previous stroke experiences also contributed to how patients reacted to their second stroke, as was the case with patient 1

> When my grandson saw that I fell for the second time in a weak he wanted to take me to the hospital. I said that I didn't want to go to hospital because with my first stroke I went there and they did nothing for me. I would rather go to the clinic the following day. My grandson called a neighbour and they put me to bed and the following day they took me to the clinic. I only told the nurses that I felt dizzy and my eyes were blurry. They gave me medication and the following day, when I saw that my right side was paralysed, I went back to the clinic and they referred me to rehabilitation.

Gehlert (2012:239) asserts that patients who were frightened by the first symptoms and sought treatment may, in time, feel capable of illness self-management as they become familiar with the pattern of symptoms. This

© University of Pretoria

heightened awareness can influence how symptoms are evaluated and in which situations patients deem it necessary to seek formal treatment, as was the case with the above participant.

Two of the patients acted immediately, including patient 4. When he realised that he could not talk nor walk, he asked for help from his neighbours. He reported his experience as follows:

> I was alone at home when I woke up and realised that my left side was weak and I could not walk or talk. Luckily, by the grace of God, I did not lock the door when I went to sleep. I waved to my neighbour through a window. Luckily, the guy came and saw that I was in trouble. I signalled to him that my speech was gone and I could not walk. He called another neighbour and they took me to a doctor in Marabastad. The doctor referred me to hospital but I did not go; instead, I went to a traditional healer in Venda.

Although stroke is a syndrome – a collection of symptoms and signs, which are usually obvious (Harwood et al., 2011:2) – most (4) patients and caregivers did not immediately recognise their symptoms as a stroke and hence they delayed seeking medical attention. The majority (3) of patients were admitted to hospital and two were not. One went to a clinic due to previous experience with hospitals, and the other one preferred to consult with a traditional healer. This illustrates the relevance of the ecosystems perspective, which emphasises that, at the macro-level, the cultural background of patients influences their choice of treatment. Those who were admitted stayed in hospital for at least a week. Harwood asserts (2011:64) that hospitalisation is crucial to proper diagnosis of the patients and provision of relevant treatment. Patients who were admitted to hospital did not explicitly mention any diagnostic procedures done or specific information given to them regarding their condition.

3.8.3.1.3 Sub-theme 1.3: Treatment received

Participants were asked to explain treatment they received during the acute and chronic phases of their stroke. They all showed preference for utilising comprehensive health care. Ross and Deverell (2010:6) assert that comprehensive care brings with it multidisciplinary approach based on team work. The South African health team includes official health care (such as doctors and nurses), supplementary care providers (such as therapists), non-official health

© University of Pretoria

care providers (including alternative health care professionals, such as homeopaths and certain herbalists, and traditional health care providers such as faith healers and prophets). The participants in the study used a combination of health care teams and this is what patient 1, 3, 4, 2 and 5 had to say:

> I do not remember what I received while in hospital but presently I receive my diabetes and hypertension treatment at DGM hospital and I only come for rehabilitation treatment in the clinic. My son has also bought me B.P. machines so that my wife can always monitor my hypertension. Besides attending the rehabilitation group every Wednesday, I also attend daily sessions at Virgin Active. I have a personal trainer who helps with the exercises.

> During my time in hospital I was a zombie living in my own world. I was confused, I think. But after I was discharged, once the strike was over, I attended physiotherapy in hospital until they transferred me to the clinic. I am from everywhere. My wife takes me to her church where they pray for me. Sometimes she brings me herbs and omega three. There was a time when my family took me because they thought my wife had bewitched me. They took me to traditional healers. My brother, who is a member of ZCC, also took me to his church. Believe me when I say I have seen it all. I am tired. I don't want anything. Not even rehab.

> I refused to go to hospital and we took the letter to my employers so that they could see that I had a stroke and would give me sick leave. My family and I believed that it was witchcraft so they decided to take me to Venda where my father was staying. When we arrived there, I was taken to an inyanga. The inyanga gave me instructions which I didn't like so I stopped consulting with her. I then went to a medical doctor in Louis Trichardt, who also referred me to Pietersburg private medical clinic. I attended treatment for eight months and I was told that I have a clot in my brain. They wanted to do an operation but my wife and father refused to sign for the operation as they didn't want to be accountable for my death. They then took me to a traditional healer in Giyani who helped me to stop using a wheelchair. I continued attending monthly check-ups at Pietersburg clinic where I was paying R600 per consultation. I'm currently talking herbs that I was told will make me walk properly. I also take hypertension treatment that I receive from the clinic and attend rehabilitation group.

> Yes, I take my high blood pressure and diabetes treatment and also attend rehabilitation group. I am also improving since I started attending the Sara Jam treatment at Nafcoc.

> When I was discharged from hospital I stayed with my brother, who is a ZCC pastor. They treated me with coffee. They really helped me and I am sharp now. I also attended speech therapy as an outpatient at

© University of Pretoria

> DGMH. The therapist at DGMH took me to many places inside the hospital. She used to give me homework and assignments. My therapist told me that she could not treat me anymore because she was moving to Arcadia. She then referred me to the clinic. My nearest clinic, which is Clinic 2, did not have a speech therapist. My son heard that there was a speech therapist that rotates between Maria Rantho, Clinic 3 and KT Motubatse. He made an appointment with the therapist. That lady helped me, she did miracles for me. I used to cry a lot. The physio and the O.T found me in a better state. I had been taking hypertension and diabetes treatment even before the stroke so I am continuing with them. They also give me aspirin.

A common thread in what was said by the participants is that they all attend rehabilitation. Ross and Deverell (2010:17) contend that stroke is a chronic disease and its medical intervention seeks to control symptoms, not to cure it. Consequently, the choice of prevention and treatment is governed by the condition that predisposes the patients to stroke (Bartels, 2011: 18), hence it is not surprising that all (5) the participants in this study were treated for pre-existing conditions that preceded stroke, such as hypertension and diabetes. Some (2) admitted that they have used a combination of western treatment and traditional healers. Another two have utilised a combination of faith healers and western treatment and one is using western and alternative care (Sara Jam). Their reaction to the illness was also influenced by their belief about causation and this determined whether they consulted western health care professionals or alternative care (Wolfer, 2012: 162). From an ecological perspective, the choice of treatment at a macro level indicates the role of culture in determining the desired treatment options.

3.8.3.1.4 Sub-theme 1.4: Understanding of stroke diagnosis

Stroke patients were required to respond to three questions regarding their understanding of stroke:

- How did you know that you had a stroke?
- What is you understanding of stroke?
- What causes stroke?

In response to the first question, most (4) of the patients admitted that they were told by the medical personnel that they had had a stroke, whereas one diagnosed

© University of Pretoria

himself as he saw that he presented with symptoms like those he had seen in people whom he knew to have had a stroke. In terms of their understanding of stroke, all preferred to explain the causes of stroke rather than defining it. They gave varied answers and their responses were as follows:

Patient 2 related:

> I was told by the nurses in hospital that I had had a stroke and they explained to me what a stroke is, but I forgot as I was confused at that time. I don't want to lie, I don't know what causes stroke.

Patient 5 explained that:

> Stroke is a funny disease which I cannot quite explain. My son and my sister were the ones who were told that I had a stroke.

Patient 3 describes stroke according to effects of stroke in his life and what he has been told.

> Stroke is not a nice disease. It has messed my life. My life is finished. My wife and the clinic told me that it is caused by thinking too much and entertaining problems in your heart, smoking, drinking and not taking pills. My family thinks that my wife has bewitched me, so I become confused. Sometimes life is hard work and is confusing.

Patient 4 explained that his stroke happened because of witchcraft. He also acknowledges medical causes of stroke.

> I was very close to my mother who died two years before my stroke. I was the only child and did not get any support from my relatives after her death. In May 2005, I did an unveiling of her tombstone and it was a big function which lasted from Friday to Monday. I think my problems started there because three days after the unveiling, on a Thursday, I had a stroke. People who came to the unveiling did not like what I did so they bewitched me with stroke.

When asked what his understanding of stroke is, he said:

> Because you are doing research, I will say stroke is caused by stress, talking too much with your heart. If you do not sleep your body gets tired and your muscles do not function well to transport your blood.
>
> My child and my sister in law were the ones accompanying me to the hospital and they were told that I had a stroke. They said stroke also causes depression. I asked what caused it and they said I have stress, but as far as I know I did not have stress. I think it is caused by tiredness and not having enough sleep.

© University of Pretoria

Patient 1 described it according to physical features that he observed:

> Nobody told me that I had a stroke but the signs I see in my body are similar to those of people who have suffered stroke. Usually, people who suffer a stroke are paralysed on one side like me, so I diagnosed myself. The rehabilitation team also asked me to join the stroke group and this, in a way, confirms it.

Although participants gave varied responses, most (4) of them mentioned that stress contributes to stroke. These sentiments are corroborated by Engstrom (2011:164) who states that psychological distress, including stress, anger, hostility and depression, has far-reaching implications for physical health. Stress directly influences the body's physiology. In a similar vein, Ross and Deverell (2010:400) add that primitive stress response prepares the body for fight or flight, and this involves biological changes such as blood clotting mechanisms. An increased clotting tendency may cause thrombosis, leading to stroke or heart attack. Some (2) participants attributed their stroke to witchcraft and another two mentioned fatigue, while another one was told that smoking, drinking and defaulting treatment also causes stroke. The responses that participants provided reflect a combination of medical information and family mythology (Rolland, 2012:334). The two participants who attributed their illness to supernatural causes such as witchcraft, consulted with traditional healers. This phenomenon is explained by Gehlert (2012:339), who says that health beliefs are guided by culture and they dictate how patients identify symptoms and how they understand the causes and treatment of their illness. This demonstrates the importance of utilising the ecosystems perspective as it shows how a person's cultural context informs their understanding of the causes of their stroke.

The caregivers' understandings of stroke are as follows:

Caregiver 5 explained his understanding of stroke as follows:

> It is a disease where, due to lack of blood flow to the brain, the brain functions are affected. People who have suffered a stroke have paralysis of one side of their body. It is mostly caused by hypertension and in my mother's case she has both diabetes and hypertension

Caregiver 1 gave a similar explanation, saying:

> I cannot claim that I understand stroke, but the only thing that I know about people with stroke is that their side, either left or right, becomes paralysed. I don't know why. Their speech and memory are slightly affected.

© University of Pretoria

Caregiver 2 and 3, believed that thinking a lot causes stroke. This is what they said:

> I think he was disturbed by the money that his son lost. He thought a lot and spoke with his heart too much. He became very worried.

> My husband was thinking a lot and he was not truthful. He was not truthful because we fought a lot. He wanted me gone from his life. His family did not want me and told him this. The mother of his child was confusing him. People he drank beer with also confused him. People who drink beer tell each other this and that, confusing each other. He used to guard me in the morning to check which car was picking me up.

When asked of their understanding of stroke, caregiver 2 and 3 said:

> I don't really understand stroke but what I do know is that stroke patients are like neuro patients. My husband looks more like a neuro patient in that he sometimes loses his mind. I worked in a neuro ward while I was at Steve Biko as a cleaner and when I look at him I see signs of neuro patients. The hospital did not say anything to me and they only said it is hypertension.

> Stroke is caused by thinking too much, not taking medication for hypertension and drinking too much.

Caregiver 4 said:

> I was not living with my boyfriend when he had the stroke but, from what he told me, I think it was caused by strenuous work. I think he was stressed and tired.

Although Harwood et al. (2011: 62) assert that, patients and their families need information on what a stroke is and what the prognosis is, this was not the case with participants in this study. Some (2) of the caregivers whose patients were admitted to the hospital admitted they were told that their patients had had strokes, but no further explanation or information was given to them as to what a stroke is. Another caregiver said she was only told that her husband has hypertension. A few (2) of the younger caregivers have insight into what a stroke is. Similar to stroke patients, some (2) of caregivers also mentioned thinking a lot as a cause of stroke. One explicitly mentioned stress and a few (2) named hypertension as the cause of stroke. Unlike stroke patients, none of the caregivers mentioned witchcraft as causes of stroke. The relevance of the ecosystems perspective is illustrated by the responses given by patients and caregivers on the

© University of Pretoria

theme of stroke onset. This shows that cultural background at the macro level informs how the people attach meaning to the illness and how this influences the desired treatment options.

3.8.3.2 Theme 2: Physical consequences

All participants in this study have suffered physical consequences of stroke. In order to explore the physical effects of stroke, the following were investigated: Neurological impairments and patient's functional abilities:

3.8.3.2.1 Sub theme 2.1: Neurological impairments

Two participants have weakness on their left side, another two have paralysis on the right side, and one has weakness on both sides. Due to a lack of detailed medical information on the patients, the side of stroke is discussed in terms of the side that exhibits weakness, not the hemisphere of the lesion in the brain. The physical consequences of stroke experienced by participants in this study include aspects related to mobility, hemiplegia, aphasia and dysphasia during the acute phase. The patients also experienced medical complications of stroke such as urinary incontinence and bowel dysfunctions in the early stages. Patient 5 and 2 described their physical consequences as follows:

> When I had my stroke, I could not do anything. I could not walk or talk. Even now, the only thing that has improved is my speech. I am still wheelchair-bound.

> My waist and legs are the most affected areas. The stroke has affected my balance and mobility. I can walk a bit but I don't have balance, hence I use a wheelchair. My speech was slurred at first but because I am attending speech therapy it is a bit better. I have pain all over my body but mostly in my hand.

Caregiver 5 corroborated her patient by saying:

> When he had the stroke, he could not do anything for himself. His whole body was weak. I used a chair and put a pillow behind him to balance him. I would tie a rope around him to make him sit. He was drooling on the side. In the early stages after the stroke we used adult diapers. His right side is working but his left side is not functioning.

© University of Pretoria

> My waist and legs are the most affected areas. The stroke has affected my balance and mobility. I can walk a bit but I don't have balance, hence I use a wheelchair. My speech was slurred at first but because I am attending speech therapy it is a bit better. I have pain all over my body but mostly in my hand.

Caregiver 2 substantiated assertion of patient 2 that things are a bit better now, compared to when he was discharged from the hospital:

> To be honest, those months were tough as I had to roll him on his side to bath him. He could not do anything; hence we had to use diapers.

Patient 1, 5 and 3 also described their physical consequences as follows:

> When I was discharged from hospital, I could not talk or walk. I could not do anything for myself. I was totally dependent on others. But my speech was the most affected. It took months before I could do things for myself but it took years before my speech improved.

> My right side is the most affected area. I cannot use my right leg and my right arm like I can my left side. My speech is a bit slurred and slow.

> At the onset of my stroke I could not do anything. My speech was gone and my left side was weak. They had to use pillows to make me sit. I struggled even to drink water because I could not swallow. I was drooling and my shirt was wet. It took me six months to be able to stand up from a wheelchair and to use double crutches. After another month, I moved from double crutches to a single crutch.

The majority (4) of participants could not do anything during the acute phase of their stroke. They could not walk, sit or speak. Two only used wheelchairs for a few months while the other two are still using wheelchairs. The physical consequences of stroke as experienced by participants in this study match those described in a study conducted by McCarthy et al. (2011), who found that stroke patients experience physical problems such as impaired balance, compromised mobility and complete paralysis in most regions of the body. These physical changes experienced by participants support the assertion by several authors that patients will experience physical disabilities such as hemiplegia and aphasia (Ross & Deverell, 2010:157) and that bowel and bladder dysfunction occurs in 30% to 80% of stroke patients, due either to lack of mobility or cognitive-perceptual impairment (Eisenberg & Rashbaum, 2011:554). Although the issue of bowel dysfunction was not explicitly mentioned, two admitted that they used adult

© University of Pretoria

nappies during the acute phase and two more mentioned that they could not do anything. These tie in with the ecological perspective, which highlights that traumatic life events, such as a stroke, represent losses and are experienced as disastrous at multiple levels (Gittermain & Germain, 2008:194).

3.8.3.2.2 Sub-theme 2.2: Functional abilities

Functional abilities were assessed in terms of the patient's mobility, communication, self-care and house work, and how these domains affected the patient's functioning.

- **Mobility**

Although problems with walking were already mentioned earlier as a physical consequence of stroke, particular attention is now paid to how patients were able to move from one place to another using any form of aid or any means of transport. All patients except one expressed that their mobility was restricted by stroke. The two patients who are still wheelchair-bound described getting about as posing a great problem. They always need assistance to move around. From an ecological perspective, the physical impairments of stroke patients negatively affect the goodness-of-fit between patients and the environment. The obstacles in the physical environment at a micro and macro level affect the mobility of stroke patients (Hepworth et al., 2013:16). Patient 2 and 3 described their mobility as follows:

> My waist and my legs are the most affected areas. I can walk a bit but I don't have balance, hence I cannot always go where I want to go. I usually use a wheelchair and still need my wife to assist me.

> I am seated in a wheelchair and there is nothing I can do. I cannot walk or even transfer myself from a bed to a wheelchair.

Patient 4 and 5 can walk without aid but still viewed mobility as a problem, described the problem in relation to what they used to do and the difficulty the experienced adjusting to walking differently.

© University of Pretoria

> I wish I could walk the way I used to walk. I used to walk long distances but now I can only walk a kilometre without assistance. I usually get tired and when I am tired I take a break.

> I am a very active person who used to travel a lot and enjoy myself. Because I am now limping, I am unable to walk long distances and I have also reduced my travelling. I only attend important functions.

A few (2) also mentioned the significance of being unable to drive.

> I used to drive myself anywhere I wanted at any time but now my movements are limited.

> I used to do everything for myself but now I can't drive my car and have to rely on my grandson to drive.

The above comments bare testimony to the assertion by Edmans (2010:183) that many leisure and social activities require transport to get to an event. She further reports that 30–40% of people who suffered a stroke were unable to resume driving and half of the patients do not get out of the house as much as they would like, even after rehabilitation.

- **Communication**

All participants had some form of communication difficulties during the acute phase of their stroke and two are completely healed, while three still have difficulties with their speech, and two are attending speech therapy. Harwood et al. (2011:210) confirm that aphasia and dysphasia affect 20% of stroke survivors and half of aphasic patients will still be aphasic six months after, whereas patients who experience dysarthria tend to recover. Patient 5 said:

> My speech was the most affected. It took years of intensive speech therapy for my speech to improve. Being unable to speak was tough. My problem was that the therapist asked me questions about what happened. I wanted to answer them but I could not. The more I tried to speak, nothing came out. I cried because I wanted to explain what happened but I couldn't; instead I would get worked up and cry. My family used to drop me off at the clinic but sometimes they could not collect me and take me back home so I had to use a taxi. The therapist used to write on a piece of paper where I was going and where I was to be dropped. When I gave the note to the taxi driver people used to stare at me and felt sorry for me. They would ask if I really couldn't speak. I

© University of Pretoria

> would try to explain but nothing came out. Presently, although I am still stuttering, at least I can communicate.

The above quote shows how aphasia as an impairment of communication interferes with the person's ability to make their needs known or to request help (Ross and Deverell, 2010:161). Inability to communicate affects a patient's functioning at the micro, meso, exo and macro levels, because they are unable to interact and participate in social activities. Societal perceptions and stigmatisation of people who cannot communicate also affect patients' functioning at the macro and meso levels. Patient 1 and 2 said:

> I never had serious problems with my speech. The only difference is that I speak slowly and softly but people can understand me, although some become impatient.

> My speech was completely affected in the beginning but now I can speak. I attend speech therapy at DGMH. My speech is slow and soft but you can hear me if you are attentive enough.

- **Self-care and house work**

Patients were asked how much they felt their situation had changed in terms of looking after themselves, with particular reference to activities such as bathing, dressing, feeding and using the toilet. During the acute stage of stroke, all admitted that they could not do anything but now at least some (2) are independent in all activities of daily living while a few (2) still cannot do any house work, but try to bath themselves with the help of caregivers. One is completely dependent and cannot do anything. Patient 5, 1, 2 and 3 recount their experiences as follows:

> After my stroke I could not do anything. I had an occasional helper who used to clean, cook and wash my clothes. He also helped me with bathing and took me to the toilet. It took five months for me to regain my strength and start doing things on my own. Luckily, I have lived with boys all my life so I am used to doing everything myself.

> I cannot cook for myself, especially pap. My grandson is too lazy to cook but, funnily enough, he knows how to eat. Our neighbour helps us to cook and wash my clothes. My grandson washes the dishes and cleans the house. In terms of self-care, I can wash my face and the front of my body. Sometimes my grandchild helps me to wash the back because I

© University of Pretoria

> have cramps in my hand that make it difficult. Usually, I bath myself like a cat. The rest, I can do.

> During the first week, I could not do anything for myself. Now, at least, I can do some activities with the help of my wife. I can wash myself in front but my wife helps me to wash the back. It is the same with using the lavatory – she helps me to get inside the bathroom but I can transfer myself from the wheelchair to the toilet. She still also helps me with dressing. In terms of household activities, I do not do anything.

> I cannot bath myself or dress myself. I am just a burden. My wife wakes me up at three in the morning to bath and dresses me. She leaves food next to me so that I can feed myself when I am hungry. I struggle to use a plastic bucket that they leave for me as a toilet. Sometimes I fall trying to reach the bucket. This is not life. Just think about eating next to your faeces. [He starts crying.]

The above statements by participants indicate that although there is clinical stability in some of the patients, their functional ability in terms of mobility and physical independence (housework and self-care) is still restricted. The patients' views expressed in this study reflect a study conducted by D'Alisa, Baudo, Mauro and Miscio (2005), in which it was found that stroke survivors were restricted in a wide range of domains, but that the greatest disadvantage occurred in the domains of mobility, occupation and physical independence. The physical consequences of stroke, as highlighted by stroke patients, show the relevance of ecosystems because they illustrate how traumatic life events such as a stroke cause transitions from being physically healthy to being a person living with disability, which leads to significant challenges and adjustments at multiple levels.

3.8.3.3 Theme 3: Spiritual, religious and cultural aspects

It has been evident in this study that religion and spirituality have numerous connections with health and well-being (Wolfer: 2012:267). The participants' spiritual beliefs influenced their understanding of their disease and their decisions regarding treatment. The relevance of the ecosystems perspective is evident, as it shows how participants use spiritual beliefs as a way to attach meaning to the illness and to cope with situations at the macro and meso levels. Many of the participants believe that God (church) will heal them. Some did not have a

© University of Pretoria

relationship with God or church before the stroke but now they do. The following were some of the points that were raised by patient 1, 5,3 and2:

> No, there are no changes in terms of my spirituality. I used to attend Roman Catholic Church but now I cannot go to church anymore. The congregants visit me. I strongly believe that God will help me heal completely.

> I never really had time to attend church before the stroke but now I can attend. I usually move from one church to another. Sometimes I attend charismatic churches, sometimes apostolic and ZCC. When you are sick, you go everywhere where people direct you. I wanted healing so I had hoped these churches would help me and indeed they did. Actually, I was helped by ZCC and I am sharp now.

> To be honest, I didn't attend church before my stroke. I go to church now with my wife. She attends these charismatic churches and she thinks they might help me to heal. Sometimes I think God is punishing me for the things I used to do. I hope God will help me die. My healing is in death.

> I attend International Pentecostal Church (IPCC) and I have told myself that this is the will of God and have hope that things will get better because there are some improvements from where I started.

Ross and Deverell (2010:35) assert that patients who attribute the causes of stroke to cultural influences are likely to use alternative care rather than western treatments. This was corroborated by quotes from patient 4 and 3 who believed that they have been bewitched and consulted with traditional healers.

> People who came to the unveiling did not like what I did so they bewitched me with stroke.

> My family and I believed that it was witchcraft so they decided to take me to Venda where my father was staying. When we arrived there and I was taken to an inyanga.

Patient 3 confirms the statement by Inniss (2011:623) that chronic illness causes patients to deal with issues of spiritual as well as cultural natures. This patient uses a combination of both religious and cultural treatments.

© University of Pretoria

> My wife takes me to her church where they pray for me. Sometimes she brings me herbs and omega three. There was a time when my family took me because they thought my wife had bewitched me. They took me to traditional healers. My brother, who is a member of ZCC, also took me to his church.

Some (3) caregivers considered Christianity to be a factor in encouraging them to deal with the burden of caregiving. Their views are in accordance with the literature by Wolfer (2012:267–275), who believes that trust in God assists people in dealing with an illness. He further alludes to the idea that religious traditions provide significant resources to help members make sense of their experiences and courage to endure suffering. This was supported by caregiver 3, 2, 4:

> Sometimes, if you are not a Christian, you will not cope because you will do everything but the patient still does not see all these things. He is always complaining and demands attention.

> Christianity really helped me. I believe that if I leave him, God will punish me. His family does not want him so, if I leave him, who will take care of him? I cannot do that to him now.

> I just told myself that God is there and will help us to get through this phase. God is my biggest supporter.

The above comments by some participants support the suggestion by Hepworth et al. (2013:226) that spirituality can provide strength during times of adversity.

3.8.3.4 Theme 4: Financial consequences

There were a number of financial and occupational changes that participants in this study had to face.

3.8.3.4.1 Sub theme 4.1: Returning to work

As Eisenberg and Rashbaum (2011:564) have mentioned, only 19% to 73% of stroke patients will return to work. From the three participants in this study who were working before their stroke, only one (patient 4) returned to the same employment and the other two (patient 3 and 5) did not return to work.

> Yes, the stroke affected me financially. It took me eight months to return to work, where I was working as a final inspector. No one could do my job better than me so they placed me where I was working before.

© University of Pretoria

> No, I didn't retire. In fact, I was a contractual worker, so when I had the stroke my contract was automatically terminated. Those people robbed me because I didn't receive one cent from them. I lodged a complaint and they said I was a contractual worker.

> I used to run a tavern. After my stroke everything stopped. The relatives told my brother because I was sick the tavern had to close. It is finished now. Everything stopped.

3.8.3.4.2 Sub theme 4.2: Added financial costs

It also emerged during the discussions that stroke creates a financial burden. The majority (4) of participants acknowledged that they have incurred additional costs due to stroke. Patient 4, 2, 1 and 3 reported their experiences as follows:

> I had R150 000 in my bank account before the stroke. Eighty thousand was used to consult with all the traditional healers and the private medical clinic that I attended after stroke. I used to have a medical aid but I cancelled it because it was too expensive, hence I had to pay cash for the consultations. Things moved from bad to worse when my company was liquidated. My condition does not allow me to search for other employment. Presently, I receive a temporary disability grant and this means that I cannot buy anything on credit and cannot plan ahead.

> I was still busy fixing my issues with my company when I had the stroke so being sick and not able to drive has delayed the whole process. I have no income so I have incurred additional costs for my son because he has to pay for my gym membership and buy us food and give us money for transport. Although I am grateful for what my son is doing for us, sometimes I do not feel right because it is like we are a burden to him.

> My financial situation is still the same. I was receiving my old age grant when I had the stroke. My grandson is not working so the two of us survive on this grant. The only additional cost is that I have to budget for petrol to attend Sara Jams at Nafcoc every week.

> Although I receive a disability grant every month, I am still struggling financially because I have to rely on my wife for a lot of things. Anyway, I am not in control of the grant because my wife takes it and just gives me R100. She told me that she uses the money to hire transport and a carer to bring me for my treatment.

One patient acknowledges that her financial status is good due to family support.

© University of Pretoria

> Financially we are OK. We have seven ventures that operate as taxis. My brother is not married. He has two children with different mothers. I don't think he will ever marry. These ventures were registered in my name and they make money. My brother gives me R1 500 every month and if the profit is high he gives me R2 000. My child is employed at UNISA. He also gives me R1 200 every month for my upkeep and still buys me groceries. I receive a disability grant of R1 300 so, honestly, I do not have financial stress.

Her views contrast with what her caregiver reported. Although the caregiver agrees that they do not have financial burdens, he acknowledges that stroke affected their monthly income.

> The tavern that she used to run with my uncle was making lots of money for them. The closure of the tavern due to my mother's illness affected their income a bit. My uncle also provides her with an allowance but I am sure it is not what she used to make every weekend. Luckily, she is content and does not complain about money. I think she realised that her health is more important than money. We all try to ensure that her basic needs are met so that she does not feel the need to work again.

Although three of the caregivers are still employed, they share the sentiments of the stroke patients that the disease has brought financial constraints in their families. These are some of their comments:

> Things are really tough. My husband used to earn R800 per week when he was still employed. He also used to do piece jobs fixing machines for the community, getting +- R1 000 per week. Since the stroke he now receives the disability grant and does not receive the full amount because I earn more than R4 000. Things are a bit tough. I might lose my job because I always take time off to attend to him and to go to all the offices that want to have sessions with us. I am not sure how are we going to survive if I lose my job.

> I am not employed and my grandfather receives an old age grant. We are managing fine because it is only the two of us but I wish I could get employment and be able to provide for myself. Presently I am unable to search for employment because he is paranoid about falling while I am away. I feel guilty to leave him.

> Before my boyfriend's company was closed, we used to be fine. Now he cannot get other employment because of the stroke so we depend on his temporary disability grant and the little that I earn as a domestic worker.

© University of Pretoria

Another caregiver stated that their financial situation is good because of family support.

> We do not have any financial problems because our third son is taking care of us. All his children are employed by this third son. He can afford to provide us with what we need. He gave us four cars. We have a van, a Corolla, a Tazz and a Mercedes Benz.

The above statements by the participants support the assertion by Brashler (2012:230) and Ross and Deverall (2010:162) that stroke disability can bring economic burden related to medical expenses, loss of income or earning potential for the individual and caregivers, rehabilitation and travelling costs. In addition, the erosion of savings and the prospect of confronting poverty as described by one of the participants can affect quality of life. Comments by participants show that financial burden is being experienced across multiple levels. The ecosystems perspective provides a beneficial framework as it shows how stroke causes financial burden on the government at the macro level, companies at the exo level, and the families at the micro level.

3.8.3.5 Theme 5: Emotional consequences

3.8.3.5.1 Sub theme 5.1: Feelings during the acute phase

Patients were asked questions concerning emotional distress and personality changes experienced during the acute phase and the chronic phase of their stroke. A dominant subject during the discussion with caregivers was the emotional toll that the stroke took on them and their patients. Harwood et al. (2011:300), suggests that depression and anxiety figure highly amongst complaints months after a stroke and half will recover within a year. In this study, some (2) of the patients acknowledged that they were diagnosed with depression during the acute phase and they were also given medication. One completed treatment and recovered from depression while another tried to commit suicide by overdosing on the medicine he was prescribed for depression and subsequently defaulted treatment. They expressed their feelings as follows:

> The speech therapist referred me to a psychologist who referred me to a psychiatrist. The psychiatrist said something about my brain and gave me medication.

© University of Pretoria

Elsewhere, she said:

> The hospital told my family that my depression was caused by the stroke.

> The social worker and the psychologist referred me to the mental doctor because I cried the whole session when I was with them. I went once to the mental doctor and he gave me pills which I used to try to commit suicide.

These two patients who were diagnosed with depression also expressed feelings of hopelessness and admitted to having experienced weeping spells.

> I am tired. I don't want anything. Rehabilitation and the exercises are painful. I just want to die. My life is painful. I cry every day of my life. Sometimes I think God is punishing me for the things I did before.

> I used to cry a lot. I lost hope and cried, cried, cried. I asked myself, why me?

Two other patients recounted similar experiences of feeling hopeless and helplessness during the acute phase of their stroke:

> I lost hope and thought I will never be the person that I was before stroke. It took two years of constant questioning why I was attacked by stroke. I used to worry about if I was dead who was going to support my family.

> It made me sad and could not sleep at night wondering, why was this happening to me? At times I lost hope and felt sorry for myself.

The above quotations express feelings of hopeless accompanied by anger or rage. Ross and Deverell (2010:55) regard anger as an integral part of mourning or grieving, where patients ask questions like, "Why me?"

One patient was bewildered and confused about what had happened to him. He stated that:

> Initially, when all this started, I was confused and frustrated because I was not sure what was happening.

After the diagnosis the patient felt relieved and this is what he said:

© University of Pretoria

> I think I am fine now because at least I know what was happening to me all those times when I was feeling dizzy and falling.

His comment is in agreement with what Ross and Deverell (2010:52) stated when they said, "When a diagnosis is finally confirmed, there is often a feeling of relief that it could have been far worse disability".

3.8.3.5.2 Sub theme 5.2: Feelings during the chronic phase

Although all (5) patients acknowledge that they experienced emotional distress during the acute phase, most (3) now admit that the disorder no longer overwhelms them but it is integrated into their new perspective (Falk-Kessler, 2011:52). One still oscillates between acceptance and sadness, as Ross and Deverell, (2010:52) have depicted. The participants explained their current feelings as follows:

> I have told myself that this is the will of God and I hope that things will get better. I see a lot of improvement from where I started to now. Some days are better than others. Sometimes I am sharp but other days I feel sad and I don't know why.

> I am healed now. I am sharp.

> I have accepted myself and have told myself that one day I will be OK. Well, my feelings are right now.

One, who still mourns his loss and has suicidal ideation, described his feelings as follows:

> How would you feel if you were dependent on others? Do you think that this is life? No, it is not life. I am tired. I just want to die. [crying]

The emotions expressed by patients in this study show what Bashler (2012:227) anticipated. He asserts that individuals usually have good days and bad days along their journey. Not everyone will pass the same stage in the same order; some may skip a stage completely while others may linger longer in a particular stage. A growing body of literature documents the emotional consequences of

© University of Pretoria

stroke on patients. Several authors (Bartels, 2011:21; Falk-Kessler, 2011:52–58; Ross and Deverell, 2010:158–159; Harwood et al., 2011:304) agree that patients experience reactions of grief, anger, relief, fear, guilt, anxiety, depression and acceptance, as demonstrated by the above comments of participants. Numerous studies such as those conducted by Thompson and Ryan (2009) and Hilari et al. (2010), who investigated life post stroke, found that patients experience emotional difficulties such as frustration, depression, anger and anxiety. The comments by participants attest to the relevance of the ecosystems perspective as it shows that the experiences of stroke on patients and caregivers are multi-faceted and these combinations of factors are interconnected. Therefore, the emotional effects of stroke on patients must not be viewed in isolation as they subsequently affect the emotional well-being of caregivers.

3.8.3.5.3 Sub theme 5.3: Patient as a person

Patients acknowledged changes in their personality and these changes, whether viewed by patients or caregivers, are generally negative. Patients saw themselves as becoming impatient, forgetful, irritable, frustrated and bad-tempered. Surprisingly, most (3) patients described their personality change in terms of socialising. They now prefer indoor life as opposed to outdoor life which they used to enjoy. They explained the change as follows:

> In a way, my personality has changed. I used to love fun and was out-going but now I prefer to be indoors.

> There are no major changes other than that I am forgetful now and I am also afraid of falling and this frustrates me. I have stopped drinking and do not go out as much as I used to. I become stressed when my grandson is not home because I think I might fall while I am alone.

> I am still the same person I was before the stroke. I have normal arguments with my wife but sometimes I get impatient with her when she does not respond to my requests immediately.

> Before the stroke I was sharp. I loved people and I did not hate anyone. I was a jolly person and enjoyed socialising. I am no longer out-going and sociable. Stroke affects the brain and memory and now I forget things easily.

© University of Pretoria

Caregivers corroborated the views expressed by patients and they also explained how the intensity of the emotional and personality changes of their patients has affected them. All caregivers reported observing changes of varying degrees in their patients. When they compared their patient's personality and emotional status before and after stroke, they frequently mentioned changes such as irritability, moodiness, aggression and impatience as being evident after the stroke.

> My husband was a loving person when I met him. He was later changed by his family and friends and became a mean and aggressive person. He was pressed and fought a lot. Now, since the stroke, he complains a lot he cannot accept his condition. He uses vulgar words, swears at me and reprimands me for no apparent reason. His language is vulgar because of depression. I really think he is depressed. He is moody and impatient with himself.

Elsewhere, she said:

> The way I see it stroke affected him mentally but sometimes he acts normal and loving and knows good from bad.

> My husband gets impatient and irritable with me and this stresses me. Sometimes he demands unnecessary attention because he just wants to see me doing things for him. He is not stable. Today he is like this and tomorrow he has changed.

> My mother used to be an active person and full of life. After the stroke she looked so helpless and that made me feel helpless as well. Her mood has improved and we are happier now, although she is no longer outgoing.

Only one caregiver attributed her partner's personality change to unemployment rather than stroke. According to her, this is what happened:

> When I met my boyfriend he had already had a stroke. He was still a loving and jolly person when I met him. His personality only changed after he lost his employment. He then started to be moody and accuses me of a lot of things that I am not doing. I just told myself that eventually things will get better.

© University of Pretoria

3.8.3.5.4 Sub theme 5.4: Emotional reaction of caregivers

As Falk-Kessler (2011:58) asserts, a patient's status may impact on a caregiver's emotional well-being, the described emotional status of patients in this study had a negative effect on caregivers. Most (3) caregivers acknowledged that during the acute onset of stroke, things were tough. They are now gradually moving towards acceptance during the chronic phase. According to Rolland (2012:220–323), families mobilise their crisis management skills more during the acute onset of stroke and they gradually accept the illness during the chronic phase as was echoed by the caregivers. Some (2) caregivers described a feeling of internal conflict or ambivalence. One acknowledged being frustrated while another adopted and shared similar feelings with his mother. Their views expressed feelings of hopelessness, frustration, depression, stress and sadness:

> It was painful when I saw my mother struggling. I cannot begin to describe how I felt when my mother used to cry a lot. I felt frustrated and at times I cried with her. Now her mood has improved and we are happier.

> My grandfather is a bit irritable with me and forgetful at times. He wants me to do things his way. He is also a bit anxious about falling. He wants me to always be at home in case he falls. This is also a bit frustrating for me because I was never prepared for all these things that he expects from me.

> My feeling is just to accept. In the beginning, it was tough. I remember people were advising me to divorce him. It was tough because I loved him. I have this belief that I have to accept because this is what God planned for me. When we are born, God already has a purpose for us. Everything is God's plan so we don't have a choice but to accept.

Somewhere else during the discussions she described a contradictory feeling.

> Things are sometimes tough for me and I cannot take this anymore and I cry a lot. For two months now, I have been forgetful and I think I am also depressed.

Another caregiver who shared her sentiments stated that:

> It hurts me and I feel bad, but what can I do? I just told myself that God is there. I have accepted my situation. To be honest, the first month was tough. By the second month, I told myself that it is my turn to struggle so I had no choice but to accept.

© University of Pretoria

The views expressed by these participants show that they have experienced acceptance as an on-going, continuous process and not a static state of being, once achieved. The feelings described by the caregivers are congruent with the conclusion drawn from a study conducted with caregivers in Johannesburg by Thomas (2008), where it was also found that carers experience emotional distress, such as depression, anxiety, frustration and loneliness. This supports the assertion by Falk-Kessler (2011:58) that stroke compromises the emotional wellbeing of caregivers and they are also at greater risk for stress, depression and anxiety. This illustrates the relevance of the ecosystems perspective, as it provides an exhaustive view into the effects of stroke on the family system. It acknowledges that, at both the meso level and the micro level, a person cannot grieve alone, as grieving depends on human interaction and support.

3.8.3.6 Theme 6: Social consequences

The data from this study revealed that, apart from the emotional and physical consequences of stroke, the patient also experiences numerous impediments to their social life. The social consequences were assessed within the ecosystems perspective, as it allows for various social dimensions to be investigated. As illustrated by the participants' comments, there is a clear rationale for giving attention to a client's relations with the wider community, their friendship network and family interaction, which reflects the meso and macro levels from an ecological perspective. In order to explore the social ramifications of stroke, the following were investigated: social activities and social support.

3.8.3.6.1 Sub-theme 6.1: Social activities

Social ramifications of stroke were experienced by stroke patients in this study in terms of lack of social participation. All patients but one conveyed a decrease in social activities. The majority (4) of patients who were more socially active before stroke subsequently reduced their activities more than the one who was less active. They acknowledged that they used to be outgoing, but now prefer to be in their own homes. The three who were attending social clubs diminished their participation as a result of social isolation and dependence on others for transport.

© University of Pretoria

One mentioned a decrease in their visiting of friends (although this was somewhat compensated for by friends visiting him) but most (4) alluded to the disappearance of friends after their stroke. Worthy of note, however, is that most (4) perceived attending stroke rehabilitation group as part of their social activities. Two also mentioned that they have ceased participation in leisure activities such as playing soccer and gardening. They recount their experiences as follows:

> I used to love fun and partied a lot. Now I stay at home and don't attend social clubs anymore. I prefer staying at home but I still keep contact with people who truly loved me and whom I love. This stroke has helped me to know my true friends. Other people that I used to party with have disappeared. The clinic is like my second home and I don't skip my treatment days. I enjoy being part of the stroke group.

> To be honest, I used to be an outgoing person, but not anymore. The social club that I used to attend before the stroke is not far from home so I still attend. My grandson drives me there because I cannot drive anymore so he is the one who drives me around and I don't like being a burden. I have stopped drinking and don't visit my friends anymore but they do visit me. I enjoy being part of the stroke group because it keeps me busy and I don't have time to think and speak alone. If I was not in the group I would be sleeping at home during those times.

> All my friends are gone. I have no one. People that I used to drink and party with are all gone. My girlfriends that I was cheating on my wife with are all gone. I am always alone at home. My wife locks me inside the house when she goes to work. The only time I leave the house is when I go to church or come to the clinic.

> I used to be a soccer player and loved exercises, hence I never thought I would be attacked by diseases such as a stroke. I am a Kaizer Chiefs fan and I used to be a club member who attended all their games. Now I don't do those things anymore. The friends that I had have disappeared. I am no longer socialising and outgoing. I don't visit anyone because I don't want them to think that I am a burden and they don't visit me. My friend now is a newspaper which I read daily. I attend stroke group, this is like a second home to me.

> I have never been an outgoing person so I never had friends before and even now I don't have friends. I only go out to do shopping with my wife and on Sundays a fellow congregant takes us to church. I still have contact with people who I used to pray with. The congregants visit me regularly and provide me with spiritual support. Gardening used to be my passion but now my wife does that. Sometimes I reprimand her because I want my flower beds in a certain arrangement and she does it her way and this frustrates me.

© University of Pretoria

The above comments by patients are in agreement with the assertion by Harwood et al. (2011:300) who suggested that stroke patients are incapable of doing activities that formed the basis of their previous social world, and therefore become excluded from it. This discovery is also consistent with the findings by Falk-Kessler (2011:59), that most patients who have sustained a stroke report a decreased involvement in social activities. These experiences have a strong link with the ecological perspective, as it illustrates how different systems interact. When stroke patients lose their physical functioning, they also lose their social support and their participation in leisure activities at meso level and micro level decreases.

3.8.3.6.2 Sub-theme 6.2: Sources of support

Various literatures (Engstrom, 2012:166; Falk-Kessler, 2011:57), attest to the significance of a supportive social network in facilitating a proper adjustment to life post stroke for both the patients and their caregivers. Sources of support that were explored in this study included the community, relationship with family, relationship between the patient and the caregiver, and the attitude of service providers.

- **The attitude and support of the community**

Most (3) patients articulated their dissatisfaction with the reaction they received from the community and a few (2) are fine with the response from the community. Three expressed that community members called them names and so they isolated themselves from them. One thinks that the community have distorted information about strokes and another mentioned that the community are curious about her condition. One admitted to receiving support from a neighbour while some (2) are being supported by the church community.

> A lot of people who attend church with me, love me and support me. There are those who heard about my condition and when they met me they wanted to speak to me so that they could confirm what they had heard. Usually, I just look at them, greet and pass them. I have my own people that I speak to. I don't just speak to people that I am not used to. People call me a lady who cannot speak.

© University of Pretoria

> No one wants to be next to me. I think people just feel pity for me but no one is willing to be close to me. Others call me names behind my back. My wife once took me to a disability home. I stayed there for two months and they sent me back home. They also treated me badly. No one wants me, they say I am difficult and I have lost hope.

> The community treats stroke victims as if we are disabled. They think that a stroke is like TB, hence they don't want to be close to us. They give us names such as sankotwana [limping person]. Sometimes they make hurtful comments about me and they pretend that they are talking about someone else.

> I have not experienced bad treatment from anyone. People treat me well. My friends come and visit me. My neighbour is very supportive and, although she works in a crèche, she always comes and checks on me after work. She is very concerned about me and will usually phone to check if I have eaten and if I have taken my medication. She is my main supporter and I am grateful.

> I do not socialise with the community but my neighbours are friendly, although we do not visit each other. The people from my church are the ones who visit me.

Interestingly, only one caregiver shares the same sentiments with stroke patients concerning the attitude of the community. He thinks that the community still lacks information on stroke and says that they tend to make hurtful comments. Some (2) of the caregiver's comments were enthusiastic regarding the support they receive from the church community and only one is being supported by neighbours.

> The community has a long way to go before they understand diseases such as stroke. I think we still have a long way to go for the community to understand it. When my mother had a stroke they said hurtful things about her. It was like she had done something evil and hence her speech was gone. Some thought she was HIV positive and her friends disappeared. Others thought she was bewitched. You do not know how many pieces of advice I was given on how to help her. I think people still need to be educated about stroke and to stop associating everything with witchcraft. Even now there are still people who like finishing her sentences for her when she speaks because they think she is taking too long. This irritates me because that is her way of practicing.

> Other community members are afraid to help us because they are scared of my husband. I used to call the ward committee before the stroke when we fought and eventually they gave up on us. After the stroke they used to come and visit but now they have stopped because

© University of Pretoria

> they feel that my husband is always complaining and whining. I have two neighbours who support me and people from the church are very supportive.

> Papa does not have lots of friends. His only friends are from church. Church members are really supportive and provide us with spiritual guidance. From my side, I wish I had someone to relieve me to take care of him. I am getting old as well so I don't have the energy to look after him alone.

The comments by a few (2) patients and (2) caregivers are congruent with the assertion by Wolfer (2012:273) that most religious groups provide significant support for their members, especially when members need it most. Other comments by participants support the statement by Ross and Deverell (2010:161) and Gittermain and Germain (2008:191) that another response to the stroke lies in the society's stigmatisation, or devaluing of the disabled person who is unable to meet the society's expectation of functioning, which leads to additional burden on the individual bearing the status. Edmans, (2010:181) further postulates that people who have had a stroke feel dependent on others, hence it is not surprising that they often lose the social contact they had before the stroke, as was experienced by participants in this study.

- **Relationship with family members**

The type and degree of support from family members varied and was viewed according to the patient's expectations. One patient reported that, besides receiving support from the primary caregiver, she also receives full support from other family members. Another one expressed that, although he receives support from his children, he still expected more help from them. Some (2) reflected on feeling that their families loathed supporting them and one expressed that distance and financial constraints prohibit his son's family from supporting him.

> We are a very close family. My parents are deceased so I am left with two brothers and my son. The way I see it, it was tough for all of us at the beginning and we struggled together. They were all there for me. My son used to take leave from work to make sure I attended therapy. My therapist used to give me assignments to do at home and my son assisted me with those assignments. My brother took me to ZCC where I got healing.

© University of Pretoria

> My only son leaves in Mamelodi and we don't see each other regularly because he is unemployed. I usually have to give him taxi fares to come and visit me. But we are fine; we communicate over the phone once in a while.

> My relationship with my children has always been complex but they relate well with their step-mother. Even before the death of their mother, we were not close except the third born who is very fond of me. After my stroke, the third born motivated the others to be close to me. We have a better relationship now but they are very stingy. My third born struggles alone to help us survive. That child is supportive and he loves me dearly. He does everything that I ask him to. He is very considerate and responsible and the others are tight-fisted.

> My family lives in Limpopo and they don't want to hear anything about me. They said I have made my bed so I must lie in it. They told me they are tired of my drama. Since I had a stroke they never visited me. They came once and took me home to Venda where they took me to the inyangas. They treated me as badly as my wife while I was there. It was horrible when I was there.

> My relatives are in Limpopo. I expect that every family loves you because of the things that you can do for them but, once you are broke, they distance themselves from you. My wife and father used to give me support when they were alive but after their death things changed. My wife's family took my child after I lost my job. My family also stopped visiting after the death of my father. I am alone now because I was the only child and both my parents are dead.

Although social support is stated as being critical in reducing caregiver strain by Falk-Kessler (2011:58), not all caregivers in the study received support from other family members. Compared to the stroke patients, most (3) caregivers reported that their families provide them and stroke patients with support, while two admit that no support is being received from families.

> You see, his family couldn't cope with him. They used to test my faith and take him. Initially, when he started complaining about me, they would take him. I would give them his pension card. After a month they brought him back. When he came back he told me about the bad treatment he received while staying there. He told me that they made him wash his blankets and he will acknowledge that I never made him do that. His family is not supportive but my family is supportive. My sister's son likes visiting him. They will talk for a long time and laugh a lot and when he has visitors he is happy and becomes proud of me.

© University of Pretoria

> Family is first-class. They all provide us with support. What makes me happy is that they do not treat me like their step-mother. It is a pity that my husband feels that they are not giving us support (like the third born) but I think they really try.

> My uncles were very supportive throughout my mother's sickness. They were there to help physically, emotionally and financially. Me and my mother are very grateful for the support they showed.

> To be honest, in the years that I have stayed with my boyfriend, I met his family once. Presently, we do not have money to visit Venda and they do not visit us either. His parents are deceased, hence his other relatives are not really concerned. I am from Free State, therefore my family is also too far away to support us.

- **Relationship with the primary caregiver**

The primary caregivers differed considerably in this study. As was described earlier, most (3) male patients were being cared by their spouses, while one female patient was cared for by her son and one male was cared for by his grandson. In total, the caregivers in this study were three females and two males. Questions about the experiences of the relationships between the caregivers and the patients prior to and post stroke elicited a diverse range of responses. From the three patients who are cared for by their spouses, a few (3) coherently stated that they have a bad relationship with their spouses. One patient admitted that they had been having marital problems long before stroke and another named unemployment as the cause of their marital problems. Interestingly, two of the patients who experience relationship problems believe that their spouses are cheating on them. Their spouses shared the same sentiments as they also mentioned having problems with their partners.

© University of Pretoria

Patient	Caregiver
My wife does not respect me at all. Even our child does not respect me at all. She treats me badly. She works in Johannesburg so she leaves home around half past three and comes back at eight. I suspect she has a boyfriend, hence she is coming back home late. I once reported her to the social workers and the situation became worse after that. She became angry and withheld food and took my disability grant. I think she is taking revenge because I used to be a bad person before the stroke. I used to beat her and had strings of affairs.	To be fair, I have never enjoyed my married life. I stayed because of the love of God. Even before the stroke he used to do funny things. I was just pushing myself. He used to beat me and had extramarital affairs. He also used to believe that women are not supposed to work so I was just pushing the matter. He was a typical traditional Venda man who didn't give wives money. I would just write the list and he would buy what he liked. Now he is insecure and when he sees me dressed and looking good he accuses me of having extramarital affairs, which I don't have. He complains a lot because he cannot go out.
I met my girlfriend a year after my stroke. Initially, when we met, she was very supportive. We did everything together until I lost my job in 2010. You know, women don't respect men who are unemployed and sick. She started telling me lies about her shifts at work and her whereabouts. Presently, I do everything for myself. I cook, clean and wash my own clothes. She does nothing for me.	Our problems are not really caused by the stroke, or, I will say, they do in a way. I met him after he had the stroke but when we met he was fine. Our relationship changed after he lost his job. He started being insecure and accusing me of having affairs, whereas I do not. Presently, he does his own things and I do mine. I stopped doing things for him because he strongly believes in witchcraft. We only share a house but we don't really live like a normal family.

Those with close relationships before stroke continued to be happy and close even after stroke, although some changes and compromises inevitably had to be made. One patient and her caregiver stated that they have a loving relationship, although the caregiver admitted that he is now overprotective.

> I was customary married to a guy who died three years before my stroke and after that I was never interested in relationships. I have a son and I love him dearly and I know he loves me too. He has a girlfriend and a five-year-old child who visits us every weekend. I am so happy and fulfilled. Anyway, in my condition I must not stress about boyfriends.

Her caregiver supported her comment, saying:

> I am very close to my mother. We were close before stroke but I think now I am a bit over protective of her. I do everything for her and I do not want to see her sad. Luckily, the mother of my child understands that I cannot leave my mother, so every weekend she visits us with my son. My mother is very close to them and cannot wait for the weekend to come so that she can see my son. My mother is caring and loves being around people.

© University of Pretoria

The above comment by the patient and her caregiver ties in with a study by Palmer and Glass (2003) who found that stroke is a shared experience and some patients reported positive aspects of stroke for family function in general. They assert that the stroke has brought them closer.

There was a definitive contrast in the comments made by one couple regarding their relationship. The husband described their relationship as being good before and after the stroke, but admits to having disagreements due to old age. The wife, however, feels that their relationship after the stroke has deteriorated due to the mental state of her husband.

> My relationship with my wife is good. The only difference is that now she takes care of me full-time. She is very considerate and helpful and she devotes all her time to me. I only reprimand my wife where necessary. As we grow old, we like disagreeing about this and that but that does not mean we are fighting. We have normal arguments. My wife always tries to cheer me up when I am down and eventually I feel better.

Although he is appreciative of what his wife is doing for him, the wife gave a different perspective of how she views their relationship before and after stroke.

> Our lives used to be very nice before the stroke. Very, very nice. We didn't have problems but now he becomes a bit aggressive. I don't take him seriously because I know his mental state is affected. Sometimes we argue about stupid things such as a programme on TV. Now I have learned to agree with him so that we do not argue.

The statement by the above caregiver echoes the results by Hartke and King (2003), which found that the emotional effects of stroke, such as apathy, low esteem and emotional liability on patients, had substantial effects on a spousal relationship.

Another patient–carer relationship has been affected by new demands brought about by stroke. They both admit that their relationship is being affected by the expectations the patient has of the caregiver, which the patient views as being valid, but which the caregiver thinks is unreasonable. Their experiences are congruent with an assertion by Rolland (2012:329) that illness in one member can profoundly affect the development goals of another member and hinder the natural flow between phases of development.

© University of Pretoria

> My grandson likes roaming around the streets, leaving me alone. I have constantly told him not to leave me alone because one day he will find me dead or in hospital. His roaming around used to annoy me before my illness but now that I am sick it makes me worried that I will fall while I am alone in the house.

> Me and my grandfather, we are fine. The only problem is that he does not understand that I have a life of my own and I have to do my own things. He does not want me to leave him alone and I always wonder how I will find employment if I am always at home. He wants me to be with him 24/7 and I cannot do that. I believe that as long as I have done my chores and he is ok I can also go out. He likes reprimanding me and I don't know why.

The above comments regarding relationships between caregivers and stroke patient showed some congruency in how both perceived their relationship. The majority (7) of caregivers and patients expressed that their relationship had deteriorated post stroke, while only (1) said the relationship had improved and two said they have the same relationship as before stroke. Amongst those who noted a change in their relationships post stroke, three attributed this to the personality and emotional consequences of stroke, while two mentioned other factors. The views expressed by the participants point to the observation by Ross and Deverell (2010:159) that stroke does not only affect an individual patient, but it interferes with the equilibrium of the family systems and affects all areas of family life. This also illustrates the relevance of the ecosystems perspective that argues that when stroke affects an individual at micro level, it subsequently affects the caregiver as well as the entire family system, as each member of the system influences and is influenced at the micro and meso levels. This is also highlighted by Harwood et al. (2011:301), who state that stroke places a strain on personal relationships because of forced changes in roles and attempts by those affected to maintain a façade of normality.

- **Sexual functioning**

Questions about sexual effects of stroke were not asked, but three patients who are still living with their partners mentioned the sexual consequences of stroke. All three explicitly mentioned decreased sexual performance as a consequence of stroke. Various reasons, such as fatigue, infidelity of the healthy spouse, physical limitations, sleeping in separate rooms and reduced sexual urge, were given by

© University of Pretoria

stroke patients for a decrease in sexual performance. Lack of intimacy has evoked feelings of guilt and embarrassment in one patient. In a separate interview, caregivers also reported having sexual intercourse less frequently or not at all following their partner's stroke. One caregiver admitted that even when they did have sex, she did not derive any pleasure from the experience. Three caregivers attributed lack of intimacy to their partners' low energy level and two cited their partners' mental state as the cause, while one mentioned old age as a contributory factor.

Patients	**Caregivers**
Everything was fine but now my performance has deteriorated. There is a difference when my wife and I are in bed. I mean I do not feel anymore. It takes time for me to get started if at all. It is like I don't feel her anymore. I feel really sad and sometimes embarrassed for being unable to satisfy my wife sexually. My experience with stroke is that it affects my whole body and my energy level drops.	My husband is a bit overprotective and jealous. He does not want me to go anywhere without him. I think his insecurity is caused by the fact that he does not have the energy to have sex with me anymore. He does not understand that I have accepted his condition and I acknowledge that we are old so I am not sure why he is jealous of me.
I think my wife is having affairs because she does not want to have sex with me. She sleeps with our son in a separate room. She bought me a bed which is like a cot. According to her, this cot is supposed to protect me from falling. I heard her having sex with another men in the other room. When I confronted her in the morning, she denied everything and said I am imagining things.	I don't know when last we had sex. To be honest, now, I feel turned off by things he used to do. Even if we try, things are not like before. He is not the same. He is weak and does not have energy. I just agree to satisfy him, but honestly, for me it is pointless. On the other hand, I am also damaged. Even now, I am still damaged. I don't have feelings, totally. I think everything contributed. He abused me. His condition is also not helping to rekindle my feelings. Presently, I will say he is trying to be a loving husband but it is too late. He does not have the energy.
You know, stroke sometimes affects your performance in bed. You will do it once when you were used to doing it more. Women start to look outside. Stroke affects your waist and legs, so you find that you cannot do like this: [demonstrating how to move your waist from left to right and we both laughed]. It is difficult to shake properly. Another problem is a lack of energy and blood flow.	My partner is not sure of himself and always accuses me of having affairs, so this turns me off. You know, when someone accuses you of such things your mental state becomes disturbed. I think what disturbs him is his lack of energy during sex, so he turns the blame on me.

The statements made by the participants in the study echo a conclusion drawn by Thompson and Ryan (2009), who found that post-stroke spousal relationships were significantly altered in terms of sexuality, sexual desire and sexual functioning. They also found that a stroke tends to have an effect on the frequency

© University of Pretoria

and duration of sexual intercourse. These authors identified several reasons for this decline, which included physical limitations and the change in nature of the spousal relationship to resemble a patient–carer relationship. Gehlert (2012:359) attests that diseases such as stroke, hypertension and diabetes often minimise the body's sensitivity to touch and stimulation, secondary to diminished blood flow.

The overall social consequences of stroke, as experienced by stroke patients and their caregivers in this study, confirm the suggestion by Eldred and Sykes (2008) that carers usually deal with a wide range of care needs, including mobility, self-care, communication difficulties and personality change in the stroke survivor. This corresponds with the study by Thompson and Ryan (2009), which found that stroke had affected the daily lives of patients and carers, including causing difficulty leaving the house, doing house work, taking care of themselves and maintaining relationships. This was congruent with the views expressed by patients and caregivers in this study.

- **Attitude of service providers**

There were contrasting responses given by patients regarding the support provided by, and the attitude of, health care providers. Some (2) patients reported that they were completely happy with the services they received in the health care setting, while most (3) had had some negative encounters. One patient reported that she was happy with the overall service at the clinic, but had had one bad experience with a nurse who was rude to her. Another patient was unhappy with the treatment he got both at the clinic and in the hospital during his first stroke, but is happy with the current clinic where he receives treatment. One other patient expressed disappointment with the psychologist and with the social worker for referring him to a psychiatrist unnecessarily. He also does not appreciate the services he receives from the rehabilitation team. These are some of the comments from participants:

> Everyone is great, except one sister who once tried to give me attitude. She argued that I belong to another clinic so I must not come to their clinic. I said, "Listen lady, you do not know my journey. You don't know how and why I ended up being a patient in this clinic. So treat me, because I don't want to relapse, and don't make me sad." I cried and went to the other nurse to complain. The nurse reassured me and told me not to panic because I am their patient. Besides that one incident, this clinic is the best. The clinic is like my best home and I don't skip my treatment days. I enjoy being part of the stroke group.

© University of Pretoria

> The attitude that I got during my first stroke was not right. I was sick and went to Clinic 3 and they told me that I am fine, which confused me. The same day, I was admitted at DGMH where they diagnosed me with stroke. The hospital kept me there without being attended. Only student doctors did their rounds but nothing was done specifically for me; hence, during my second stroke, I didn't bother going to the hospital. My current clinic is good and it is good being part of the rehabilitation group.

> I am happy with the service that I am receiving in rehabilitation. The staff members are friendly and have time for us.

> People in the clinic are right and they motivate us. There is open communication between us.

Harwood et al. (2011:301) confirm that patients are usually frustrated by what is provided and two thirds are dissatisfied with the support they receive from health and social services, as was illustrated in this study. Ross and Deverell (2010:164) argue that although health care professionals cannot reverse stroke, they can improve the quality of life of patients and their families. The services received by the patients in this study show how the health care system affects the experiences of stroke patients and their caregivers, and underlines the relevance of the ecosystems perspective in assessing how such systems add to the limited resources at exo level.

3.8.3.7 Theme 7: Patient's greatest loss

Patients were requested to describe what they perceived as their greatest losses and their caregivers were also requested to describe the impact of stroke on the patient from their perspective. The general feeling shared by both patients and their caregivers was that the loss of mobility (either walking or driving) was the greatest loss, followed by finances. The majority (3) of the patients and some (2) caregivers mentioned walking and a few (2) patients and the majority of caregivers (3) reported driving as the patient's greatest loss. Two patients find it difficult to adjust to walking differently. One patient and her caregiver mentioned social life. Other caregivers named the inability to self-care and decreased self-esteem as the aspects of their patient's life that were most affected.

© University of Pretoria

My greatest loss is….I lost people. Actually, I didn't lose them but my eyes were opened as to who my true friends are.

My greatest loss is driving. Although my grandson drives me around, I do not like being a burden.

Being unable to walk and drive is my greatest loss. I know I can walk with help but I wish I could walk the way I used to. My movements are also limited because I cannot drive.

Hmm, where to start? I will say, everything. You see, I used to walk and work for myself. I don't see myself as a man anymore. I used to make money for myself but now I am dependent on these horrible people.

My biggest issue is my movement. I wish I could walk the way I used to. Everything is back to normal except my movement. Financial security is also my greatest loss. I used to earn a reasonable salary but now I am dependent on a disability grant which I have to renew every six months.

Impact of stroke on the patients from the caregivers perspective:

The stroke has had a negative impact on him. Have you seen a situation where you were born normal and can walk with your own legs and now you cannot do anything for yourself? That's difficult. Suddenly you cannot do anything and things becomes tough for you. The reason why my husband has depression is that he dislikes being dependent on others. We are talking about a person who used to like going out and having fun. Everyone in the community knows him. His biggest source of stress is that he used to work and entertain people and people used to love him, but now he cannot do all those things. He was alive and didn't care that people were using him. Now it is me giving him money. I cannot maintain his previous lifestyle. If I give him R100 today, I will not have money to give him tomorrow. The other thing that stresses him is the toilet. The fact that he has to wait for me to return from work to take out the bucket toilet stresses him a lot. Even if my daughter-in-law is at home, culturally, she cannot take out his toilet, let alone clean him.

It has affected a lot of things but I think the most affected part of his life is driving. He complains about being unable to drive. The fact that he cannot drive really hurts him. We have four cars which his son gave to us so but now he cannot drive them. He cannot stand up and his mind is also affected. He used to be an active person doing things around the yard.

© University of Pretoria

> To be honest, I think he is stressed by not being able to drive himself and go wherever he wants. He cannot visit friends that he used to hang out with. I am not sure why he is forgetful and irritable.

> His self-esteem and his finances are the most affected parts. He always thinks that people talk about how he looks and walks. He accuses people of saying things about him and thinks friends are no longer interested in him because he does not have money. He also thinks that I don't respect him or love him anymore because he is unemployed. All these things are in his imagination. [His greatest loss is] definitely his social life.

> Mom used to be outgoing and loved fun. She used to be a member of social clubs that met every month but now she has stopped all those activities. She was also running a tavern and she was working very hard. She used to sleep very late because she was entertaining customers. In a way, the stroke has helped her because the tavern is closed and she has enough time to rest and be on her own.

The greatest losses described by participants in this study correspond with a study by D'Alisa et al. (2005), in which it was found that patients articulated their concerns about stroke in terms of loss of functions, especially mobility. They further expressed that lack of mobility restricts their participation in daily activities and their social lives. Their experiences are also supported by Harwood et al. (2011:192) who highlight that the loss of mobility is fundamental to many problems faced by patients. If you are immobile, it is difficult to maintain continence, dressing, house work and occupation. However, this is at odds with a study by Thompson and Ryan (2009), who found that emotional difficulties are rather more distressing to participants than physical limitations.

Strikingly, patients and caregivers are mostly concerned with independence rather than emotional issues. They emphasised financial losses, mobility and social life in general. The greatest losses indicated by patients show that within the ecological perspective, experiences of stroke patients are a combination of multiple levels of influences, with changes in physical abilities leading to compromised functioning and various losses, including economic and social.

3.8.3.8 Theme 8: Caregiving burden

The burden of stroke on caregivers was investigated, exploring aspects such as day-to-day tasks, health problems due to caregiving and distress. The experiences

© University of Pretoria

of caregivers in this study, as illustrated below, confirm the statement by Harwood et al. (2011:301) that looking after a stroke patient has physical, psychological and social consequences. Harwood et al. further assert that carers report emotional distress and tiredness, half of carers report physical ill-health and two thirds report limitation of social activities. All these sentiments are shared by caregivers in this study. The ecosystems perspective provided a beneficial framework for exploring the entire context of the caregiver's experiences, which include physical challenges of caregiving at the micro level, to social implications at the meso level.

3.8.3.8.1 Sub-theme 8.1: Day-to-day tasks

Two caregivers, whose patients are independent in activities of daily living, are employed and therefore do not have day-to-day duties in their care of the stroke patients. For the rest, the most challenging tasks of caregiving were specific to each caregiver, because their patient's functional abilities were all different. All (3) mentioned that part of their task is to ensure that the patients have taken their medication.

One caregiver, whose patient is only semi-dependent, has different tasks from the others whose patients are completely dependent. His daily routine includes, preparing breakfast, running a bath for the patient and driving him around. The other two caregivers' tasks range from assisting the patients with self-care needs and doing house work.

> My duties are to bath him and make sure he is OK. In the morning, when I wake up, I clean the yard and go and check on him. Actually, before doing anything, I start with him first. I check if he slept well and greet him. I check outside and then prepare his room and wash him. From there, before seven, I give him his breakfast and his pills. This is the routine when I am off duty. On days when I go to work, my schedule is different. I leave home at three-thirty in the morning. Before I leave I make sure that I have prepared his meals. I put food in the fridge and put his Kellogg's or Movite next to him. I also leave his fruit and water. My daughter-in-law is not always available so I leave things where he can reach them.

The researcher asked her who baths him and takes him to the toilet when she is at work.

> I wake up at two and leave home at 3:30 am. I bath him before I leave. I made a chair for him. This chair is made out of wood. I covered it with cloth and covered that with plastic. I cut a hole and placed a bucket underneath. His right hand is functional so he uses it to transfer from a wheelchair to this bucket toilet using a bugler door frame to help him

© University of Pretoria

> stand up. Initially, when he had the stroke, he used to wear adult diapers. You know, when he was still weak I used to wash his pants and linen. I would wash, wash and wash every night after work.

> When I wake up in the morning I inject him with diabetes treatment and give him hypertension treatment. His son bought him a BP machine so I check his BP every morning. Sometimes he cannot bath himself properly so I help him with that. I prepare his room and make breakfast for him. In between, before lunch, I give him snacks and later I prepare his lunch and give him his afternoon snack as well. I also assist him to turn when he is sleeping. It is difficult for him to turn. He can take himself to the toilet but sometimes he struggles to transfer from the wheelchair to the toilet then I assist him. When he tries to go to the toilet by himself, the activity takes time.

> In the morning, I help him with exercises and prepare his breakfast and give him his medication. I clean the house and pour water for him to bath. I do not know how to cook so our neighbour does that for us. I drive him where he wants to go, including coming to the clinic, attending Sara Jam at Nafcoc, attending social clubs and doing shopping.

The experiences expressed by the participants above coincide with the literature by Gittermain and Germain (2008:302), that painful life events such as stroke disrupt family life and the changes include reorganisation of roles, tasks and routine.

3.8.3.8.2 Sub-theme 8.2: Health problems

Caregivers were asked whether they felt their health had been affected by taking care of stroke patients and only a few (2), whose husbands are still using a wheelchair, admitted to experiencing health problems. The main consequence they described was exhaustion due to the physical strain of carrying the patient.

> I am tired really tired. In January, I was booked off because I had pain in my shoulders. For two months now, I have been forgetful I think I am also depressed. Can you imagine having to pick up someone of Mr M's weight? I am really strained.

> The last time when he came back from the hospital, I consulted with the doctor. Things were a bit hectic and my shoulders were painful from carrying him. It is only me and him in the house so I have to do everything from cleaning the house to washing clothes. This means I am always working and this tires my body.

© University of Pretoria

These findings correlate with the assertion by Ekstam et al. (2011:50) that the inability of persons who have suffered a stroke to carry out daily activities negatively affects their partners' health.

3.8.3.8.3 Sub-theme 8.3: Aspect of distress for caregivers

The two caregivers whose patients are completely dependent indicated that caring for a stroke patient is draining, both emotionally and physically, but they stressed that the physical strain is worse. The other three only mentioned the mental strain of caregiving. One indicated that an additional stressor was loss of independence. Their experiences support a finding by Wasserman et al. (2009), that high patient dependency levels and a lack of support are predictors of adverse outcome in caregivers.

> A stroke is very disturbing, especially if you don't know what to expect. People who have suffered strokes are very moody so you have to accommodate them. If he is angry, give him space. My husband is impatient with himself. I think the physical and mental strain is the same, but for me, pulling a person is very tough. My husband is heavy. Remember, it is only my energy that is used and my husband is not helping me. This is the reason why I made a bucket toilet for him, because it was tough for me to take him to the toilet.

> I cannot go where I want to go but it does not help to complain that I don't have time of my own to do my own things. I am unable to catch a taxi and go shopping on my own like I used to. My other challenge is the physical and mental strain of caregiving. The first month was physically straining when I had to roll him to bath him and feed him. Now he can get into the bath but I still help him.

> For me, staying with someone who has had a stroke is emotionally draining because I have to deal with his irritability, being reprimanded for no particular reason and the expectation that I must always be with him.

> I only see my husband in the afternoon after work so I only have to deal with his moods swings then. So, for me, the mental stress is mostly caused by his suspicious mind.

© University of Pretoria

> During the early stages after the stroke, the physical strain of carrying was the worst. But once the condition had stabilised we only had to deal with the mental strain.

These results echoes the results of a study by Eldred and Sykes (2008), that carer burden can include financial loss, as well as physical and mental strain. This is supported by Ross and Deverell (2010:18) who argue that stroke can place intolerable strain on caregivers because of the need for high levels of physical care and support, and the emotional connotations associated with giving help.

3.8.3.9 Theme 9: Coping strategies

The caregivers were asked about their coping strategies. Some (2) considered Christianity to be a factor in their ability to cope. They described their strategy in accordance with the literature by Wolfer (2012:267-275), who notes that trust in God appears to enhance one's sense of control and to promote active coping. He argues that religious traditions endorse forgiving attitudes and behaviours, as is illustrated by the comments of the caregivers below. Other caregivers (2) mentioned that care skills and patients' positive attitudes influence their coping. The importance of these factors is stressed by McCarthy et al. (2011: 145) who argue that optimism, hopefulness and adaptive coping may protect participants from experiencing mental health complications.

> Sometimes, if you are not a Christian, you will not cope because you will do everything but the patient does not see these things. My husband is always complaining and demands attention but I can cope because I took care of my mother who had a stroke as well. I did a first aid course so this background also helps me. The most painful part is the lack of support from his family. That makes me feel lonely, very lonely. But what you have to do is be caring. I bought him a TV and a radio to entertain him and reduce his stress. I don't want him to feel lonely.

> If I was not a Christian, a born again Christian, I would have left a long time ago. I would have felt hurt and held him responsible for things that he did to me. He burned my clothes, spent his money on friends and family and his family does not want me. I would count every bad thing he did. Christianity really helped me.

> I just told myself that God is there and will help us to pass this phase. You know, things are better now compared to the earlier days. What

© University of Pretoria

> gives me strength is his willingness to be healed. He participates in exercises. When I see him sad, I brush him on the shoulder and crack jokes for him and eventually he laughs. My experience with neuro patients helped me to ignore some of the things that he does. God is my biggest supporter.
>
> I wish my mother or at least my grandmother was still alive to deal with all these things. I just hope that my grandfather will get better and things will get back to normal. For now, I just ignore him when he reprimands me and I give him space.
>
> I cannot say we are coping because we have long passed the stage of coping. To be honest, now we are fine and I think the worst is over. The days when we were stressed are over now. I know my mom's speech and her movement are not yet completely sharp but we are hopeful that she will get better. What motivates me is that she still attends treatment and she is positive that her health will be back to normal. I am also happy that she appreciates everything that is being done for her and she is not stressed by anything.
>
> My approach towards the whole thing is to ignore him when he does his funny things. I just don't pay attention to his comments because I know he just wants to cause fights.

The participants' comments are congruent with the statement by Hartke and King (2003) that mediators, such as care skills, education regarding disability, and a support system, can positively influence coping and distress. Rolland (2012:323) argues that, often, families come to grips psychologically during the chronic stage of stroke, by which time they have devised an on-going coping strategy. The coping strategies employed by caregivers highlights the importance of social support and social networks, at meso, exo and macro levels, in enhancing coping as depicted by the ecosystems perspective.

3.8.3.10 Theme 10: Recommendations

The recommendations made by participants are discussed below.

3.8.3.10.1 Sub-theme 10.1: Recommendations to stroke patients

Participants gave diverse recommendations, but themes that emerged frequently from stroke patients is that other stroke patients must live healthy lifestyles, which means adhering to treatment, eating healthy food, having hope, and respecting

© University of Pretoria

and accepting their situation. One participant alluded to the fact that the patient's behaviour influences how caregivers will respond to their illnesses.

> People who have had a stroke must have patience. They must not give up on themselves and they must follow the treatment prescribed to them. Sometimes the tasks that are given to you might seem useless but, in the end, they do help.

> Patients must respect health care workers.

> I would encourage them to accept how things are. Sometimes patients create problems within families because they pity themselves. If you lose hope and pity yourself, your family will tell you that you should have died the day you had the stroke [laughs].

> Patients must also eat healthily and must not eat fatty foods.

3.8.3.10.2 Sub-theme 10.2: Recommendations to caregivers

Both caregivers and patients strongly feel that caregivers must love themselves and their patients, and must have tolerance, patience, understanding and a strong personality. They must encourage their patients to adhere to treatment and find new hobbies. They must also rely on prayer.

> The first days after stroke are tough but, as times go by, things become better. Caregivers must be patient and not take things in a negative way. They must have patience because stroke patients are drooling and cannot stand up and need to be bathed, especially in the early days. As a carer, you need to be nice to them and do not hurt them. You must handle them nicely, even when you take them to the toilet. They must not see pain when they see you.

> I suggest that they must have patience and love, and they must not do it because they have to. You must have time because sometimes patients refuse even to bath and they cry a lot. Do not just say hello and then ignore them. You have to bath them and speak to them. TV is important. My husband has a TV and he prefers to speak to characters such as Ben 10 and he laughs a lot when he is watching them. His mood improves when he watches movies and DVDs. We laugh together when he watches the DVD of our wedding day. He tells me stories of things he did before and after the wedding and laughs. As a carer, you have to love yourself in order to be able to love your patient. If they are angry, give them space.

© University of Pretoria

> Carers must hang in there and have the heart to be patient and strong. They must be patient because stroke patients do not do things deliberately to hurt them; it is only that their minds are affected. We must accept that it is our time and never ask, “Why me, why me?” The biggest thing is prayer.

> They must just be patient.

> Living with a stroke patient has taught me that a caregiver needs to be understanding and patient. There were times when my mother was confused and all she needed was for me to be loving and patient. Another thing I realised is that they need support in terms of taking their medicine. They need to be reminded constantly.

> I think staying with a stroke patient requires someone who understands. You have to know their mood swings and be able to deal with them.

3.8.3.10.3 Sub-theme 10.3: Recommendations for service providers

Recommendations for improving service delivery suggested by both patients and caregivers included: that they be provided with information on stroke as a disease, and on its impact and how to deal with survivors; that proper assessments must be done; that exercise equipment, such as machines and weights, should be procured; that they be provided with proper counselling and support. An additional concern was the lack of respite facilities for stroke patients. They applauded clinics for providing them with good services and encouraged them to continue with motivations, excursions and support groups for patients. Support groups for caregivers should be established as well. A concern was also raised that permanent staff should be hired.

> I feel at home when I am here. The trips that we usually take with our therapist really help. They make us part of the community and we forget about our problems.

> Exercises are good and they keep us healthy, therefore I would like the clinics to continue with them. I wish the hospitals could be like clinics and give us attention when we are there. I also feel that, if my first stroke was really attended to by both the clinic and the hospital, I might not have had the second stroke.

© University of Pretoria

I have not been to different places so I cannot make comparisons. I will just say the staff must keep up the good work. We also need information on how stroke affects us.

I would like them to continue motivating patients who are hopeless. They must tell them that things will get better and that not all stroke patients die. Recovery depends on taking treatment and being positive. I want the rehabilitation facility to buy more equipment and machines for us. We only have one bicycle and we need dumbbells as well.

The social workers must help us to build our families. They must teach us to have lots and lots of love. I know it is painful, but they have to teach us how to cope. There are times when things are tough and they must teach us not to put things on our shoulders. There is this woman who had similar problems to mine, so sometimes I consult with her. I think meeting with people who have the same problems can also help. Her husband used to abuse her and now he is in a wheelchair. The husband has now changed and their life really motivates me. When I am with her, we share our experiences and laugh together. Lastly, I wish there was a proper place where they could take care of my husband while I am at work.

I am a living testimony that patience is the key. I will advise the team to continue giving exercises to the patients. They must make sure that their patients take treatment. They must have love as well. I know that stroke patients are very rude, but just be patient. The nurses must be humble, even when their patients are high. They must be like husbands and wives. As women, when our men are angry, we go outside and give them space. Nurses must learn to apologise.

Support groups in the clinic comfort stroke patients and makes them happy. I wish there were support groups for caregivers as well. Hospitals must also try to explain things to us when patients are admitted. They just told us that we must take care of the patients but did not prepare us for what to expect from the patients. I am coping because of my experience working with neuro patients but I think that caregivers who are clueless will struggle to take care of patients.

I wish they had told me how to deal with my grandfather's mood changes. I also need home-based care nurses to assist during the day while I go look for employment.

I think proper counselling should be provided to stroke patients because I do not think my boyfriend is dealing well with the fact that he cannot be employed. He also thinks the worst of people and thinks that they are plotting against him, so he needs counselling.

© University of Pretoria

> To be honest, I am impressed by the services that my mother receives in government clinics. I cannot comment about hospitals because her stay there was short. The support group does wonders for her. She gets excited every time she goes to the group. The professionals and the group really helped to improve her mood. My only wish is that the department can hire permanent therapists because since my mother became sick she has been treated by at least four speech therapists. It's like she is getting a new therapist every year.

Participants are not satisfied with the information they received from hospitals about their illness and stroke care. Caregivers expressed a need for a support group for them as well.

3.8.4 Summary

This section focussed on the empirical study to investigate the experiences of stroke patients and their caregivers following a stroke. A detailed description of the methodology used was provided as well as the empirical findings. The findings indicated that stroke symptoms were not obvious to participants; hence they delayed seeking medical assistance. Choice of treatment and medical assistance sought was based on the participants' belief about causation of their disease. Patients experienced jarring physical, emotional, social, spiritual, and financial consequences of stroke. Caregivers also experience diverse burdens of caring, such as physical and mental challenges associated with caregiving, relationship disruptions, financial strain and loss of independence. Coping strategies and recommendations were also highlighted. The themes were integrated with literature and most findings corresponded with findings of various previous studies done on the effects of stroke on patients and caregivers.

The next chapter will present the broad conclusions and recommendations that can be drawn from this study.

© University of Pretoria

4. CHAPTER FOUR: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

The aim of this chapter is to present the conclusions drawn from the study, based on the literature study and the empirical findings of this study. The summary will cover the goal and objectives of the study and how they were achieved, key findings, conclusions, and recommendations of each theme.

4.2 Summary

4.2.1 Goal and objectives of the study

The goal of the study was to explore the psychosocial experiences of the patients and their caregivers following a stroke. This goal was achieved by pursuing the following objectives:

OBJECTIVE 1

- **To conceptualise and describe stroke as a phenomenon**

As a way of achieving Objective 1, Chapter Two provided a description of stroke. The causes, risk factors, symptoms and different treatment regimens were also discussed. In the empirical study, it was established in Theme 1 that participants experienced similar stroke symptoms as those described in various reviewed literature. Participants gave a clear description of people who have suffered a stroke. They confirmed that the stroke occurred suddenly and within seconds they experienced weakness of the arm and leg, and could not talk or walk.

OBJECTIVE 2

- **To explore and describe the physical impact of stroke on the patient**

This objective was achieved through the literature study in Chapter Two and through the empirical study in Chapter Three. The participants' responses in Chapter Three correlate with assertions by various authors in the literature. Theme 2 dwelled on physical changes which included neurological impairments (Sub-theme 2.1) and functional abilities (Sub-theme 2.2). Patients assert in Sub-theme 2.1 and Sub-theme 2.2 that they have experienced many physical adjustments

© University of Pretoria

such as decreased mobility, speech impairment and reduced self-care abilities due to stroke.

OBJECTIVE 3

- **To explore the emotional, social, religious and economic experiences of the patients and caregivers following a stroke**

The above objective was discussed thoroughly in the literature study in Chapter Two. It was explored again during the empirical study, in which it was found that stroke affects the quality of life of patients and caregivers as it intrudes into their emotional, social, spiritual, religious and financial well-being. In Theme 3, it was noted that there is a connection between patients' spiritual and cultural beliefs and how they react to and treat their stroke. In Theme 4, it was illustrated that patients suffered financial burden because they were unable to return to work and they incurred additional medical costs, as depicted in Sub-theme 4.1 and Sub-theme 4.2. It was also established in Theme 5, Sub-theme 5.1 and Sub-theme 5.2 that patients experience personality changes and their emotional well-being is affected. Participants revealed in Theme 6 that their social activities had declined (Sub-theme 6.1) and that their relationships with family members, community members, spouses and primary caregivers were disrupted by stroke (Sub-theme 6.2).

OBJECTIVE 4

- **To explore the challenges of caregiving following a stroke**

It was established in the discussions with caregiver participants that stroke does not only affect the individual patient, but it also disturbs the equilibrium of the whole family. In Chapter Two and Chapter Three it was illustrated that experiencing a stroke in the family is disruptive to family members, as caregiving tasks are assumed and this creates carer burden (Theme 8, Sub-theme 8.1). Carer burden, according to different quotes of participants, includes physical health problems, financial loss and emotional problems. They highlighted in Sub-theme 8.2 and Sub-theme 8.3 that the greatest challenges were mental, as well as physical strain.

© University of Pretoria

OBJECTIVE 5

- **To make recommendations for social workers in intervening with stroke patients and their caregivers**

The objective was achieved through a thorough discussion in Chapter Two of the ecosystems perspective as a beneficial framework for exploring the experiences of stroke patients and their caregivers. It was also achieved through the recommendations by participants in Chapter Three, where they highlighted changes they would like to see. The empirical study established that participants want more information and support from social workers and all health professionals. Establishment of support groups for caregivers was also highlighted as a need.

4.3 Key findings, conclusions and recommendations

The aim of this section is to present conclusions drawn from the key findings of the study, and to make recommendations based on the conclusions.

4.3.1 Biographical details of the patients and caregivers

4.3.1.1 Key findings and conclusions:

As reflected in Chapter Three, the demographic details of participants consist of age, gender, marital status, employment and diseases before stroke.

All the stroke patients who took part in the study were older than 50 years. Only black patients took part in the study and this was mainly due to the fact that the study was conducted in Soshanguve, where the population is predominately black. Both widowed and married patients participated, with the majority being males and only one woman. Most fell into the middle income group, as the majority (3) were employed before the stroke and only two survived on old age grants and disability grants. Although participants were independent in activities of daily living before stroke, all have hypertension and three have a combination of hypertension and diabetes. Only one had had a previous stroke.

From the findings, it can be concluded that people who suffer a stroke vary with regard to gender, marital status and socio-economic factors, hence the relationship between incidence of stroke and social class is considered of little

© University of Pretoria

significance in this study. It can also be concluded that the greatest risk factors of stroke as described by participants in this study are age, pre-existing conditions such as hypertension, diabetes and previous stroke.

All participants were older than eighteen years, as per inclusion criteria. Their ages ranged from twenty-four to sixty-five years. Both males and females participated and the majority cared for their spouses while others cared for their parents and grandparents. Their economic status also varied as some were employed whereas others were unemployed.

It can be concluded that most stroke patients are cared for at home by family members, partners or children. Caregivers are most likely to be spouses, as stroke is more prevalent in the elderly, as shown in the demographics of patients. It can also be concluded that not one characteristic can be used to describe caregivers as their social class, such as gender and economic status, varied.

4.3.1.2 Recommendations:

- Educational awareness programmes should be instituted to increase public awareness of stroke and risk factors.
- More effort must be put into early detection and treatment of hypertension and diabetes, as there is a definite association between these conditions and stroke. Mass screening should be conducted regularly.
- All role players should monitor treatment and compliance to prevent stroke.
- Interventions should target families as they are the most probable caregivers and programmes should be developed specifically to support caregivers.
- Additional support should be developed, especially for elderly caregivers who are prone to developing health problems due to stress of caregiving.

4.3.2 Theme 1: Onset of stroke

4.3.2.1 Key findings and conclusions:

This theme revealed that stroke occurrence was sudden in all participants. Symptoms experienced by stroke patients included weakness on one side, as well

© University of Pretoria

as difficulty seeing, walking and talking, but patients did not recognise the signs as stroke. Worthy of note is the fact that, while some reacted immediately to the symptoms by seeking medical help, others delayed seeking medical help as they did not recognise the signs as symptoms of stroke. Participants consulted, and are still using, a combination of different types of health care workers. Participants' beliefs about causation of the disease influenced which health practitioners they consulted. Those who attributed the cause of their diseases to supernatural powers, consulted with traditional healers, whereas others used western treatment. Those who went to the hospital were only told that they had stroke, but no thorough counselling was done and they are not aware of treatment and diagnostic procedures that were done.

Based on this finding, one may conclude that stroke is a condition of sudden onset, that participants have little understanding of stroke, and that their reaction to the illness was influenced by their belief about causation. It can also be concluded that various factors, such as previous history, culture and spirituality, inform the frame of reference that patients use to deal with diseases such as stroke. Based on the quotes of participants, it can be concluded that there is a trend towards shorter stays in hospitals; hence, family members automatically assume carer roles without being prepared and without adequate counselling. It is also not clear whether patients received confirmatory investigations such as CT scans while in hospitals because they cannot remember as they were confused. These findings show that a lot of problems emanate from the macro level, where the general population lacks information about stroke and its causes. Therefore, cultural beliefs influence the type of treatment they sought. Challenges were also found at an exo level, where patients are discharged from public hospitals without receiving adequate medical and social services and there are limited resources such as a complete lack of CAT scans. Recommendations to address these challenges are based on the ecosystem perspective, as it provides a framework that considers intervention strategies from the macro level: educating the public about stroke, while considering cultural and spiritual backgrounds. Services at the exo level are also essential to address the loopholes in the departments.

© University of Pretoria

4.3.2.2 Recommendations:

- The public and health workers should be educated about the warning symptoms of stroke and the need for rapid response.
- Patients exhibiting these symptoms should be referred for prompt medical evaluation.
- Diagnostic procedures such as observation of clinical features and diagnostic tests should be performed on all patients.
- Protocols for the management of stroke care in hospitals should be developed, with clear responsibilities for all multidisciplinary team members.
- Training for multidisciplinary teamwork, which integrates the work of different disciplines, is essential.
- Co-ordination of referral systems between hospitals and primary health care clinics should be improved.
- Families, patients and caregivers need continued guidance, information and support.
- Patients' cultural beliefs should form part of the assessment to enable practitioners to provide culturally relevant interventions.

4.3.3 Theme 2: Physical changes

4.3.3.1 Key findings and conclusions:

The findings highlight that patients suffer physical consequences due to stroke. All patients suffered either paralysis of one side or both sides of the body, making this a distinguishing feature of people who have suffered a stroke. Stroke caused many physical disabilities to participants, such as inability to walk, talk and perform self-care and house work activities during the acute phase. Although the majority of participants were clinically stable during the chronic phase, they still experienced physical disabilities that restricted their mobility and ability to perform self–care. The majority of participants acknowledged that they need assistance from their caregivers to perform activities of daily living.

© University of Pretoria

The conclusion can be drawn that stroke causes physical disabilities such as restricted mobility, hemiplegia and communication problems. It is also evident that when these physical aspects are compromised, patient functioning is affected. The ecosystems approach is cardinal in stroke intervention, as it provides the opportunity to explore the link between physical disabilities and patients' functioning, as well as providing an opportunity to explore continuity of stroke care on different levels.

4.3.3.2 Recommendations

- Goal-oriented programmes aimed at improving physical health and better communication should be developed for each patient.
- Integration of continuity of stroke care between hospitals and primary health care facilities should be strengthened to ensure that patients receive physical and cognitive rehabilitation.
- Caregivers should be provided with home programmes to assist patients with exercises at home.
- Programmes are needed to replace the loss of patient activities and functioning.
- Regular home-visits are needed to reduce environmental obstacles that hinder patient functioning.

4.3.4 Theme 3: Spiritual consequences

4.3.4.1 Key findings and conclusions

The findings indicate that the spiritual aspect of participants was not greatly affected, but that the spirituality and relationship between God and the participants was strengthened. The majority of participants acknowledged that they did not attend church before the stroke, but now believe that the church has contributed to their healing. Caregivers also acknowledged in Theme 11 that their spirituality assisted them to cope with the burden of caregiving.

© University of Pretoria

It can be concluded that although the majority of participants indicated that their spirituality did not change, they still used spirituality and culture to guide and inform how they construed causes and sought treatment for their illness. Participants' belief systems assisted them to cope with the effects of stroke. It is also evident that there is a connection between the spirituality and well-being of patients and that it can also act as a source of support for patients and caregivers. This highlights the appropriateness of the ecosystems approach, as it focuses on tapping different resource systems, such as belief systems, to help patients cope with their experiences.

4.3.4.2 Recommendations

- Multidisciplinary teams must always be informed about their patients' cultural and spiritual background and how it influences their experiences so as to provide culturally and spiritually competent interventions.

4.3.5 Theme 4: Economic consequences

4.3.5.1 Key findings and conclusions

The majority of participants in this study were unable to resume their pre-stroke work and this created financial burden. Additional costs related to travelling and medical treatment were also described as adding to financial strain. Erosion of savings through consultation with different health care workers was also mentioned as one of the consequences of stroke.

It can be concluded that medical costs add financial strain to stroke patients as all patients in this study utilised different health practitioners and hence additional costs, such as transport fares, were incurred. Exo-system issues, such as discrimination of people with disabilities by the labour markets, intersect with micro level issues of financial burden at home; therefore, the utilisation of the ecosystems perspective is relevant, as it provides a holistic framework which locates all the different elements of people's lives and the connections between them (Jack, 2010:130).

© University of Pretoria

4.3.5.2 Recommendations

- Stroke patients who were in paid employment prior to the stroke should have access to vocational assessment and rehabilitation.
- Occupational therapists should be trained more intensively in the field of vocational rehabilitation.

4.3.6 Theme 5: Emotional consequences

4.3.6.1 Key findings and conclusions

The findings exposed various emotional consequences of stroke for the patients and their caregivers. Participants experienced confusion, depression, anger and hopelessness during the acute phase. They also acknowledged that their mental state is not static and it changes over time, ranging from confusion to acceptance. They also described feelings of ambivalence and viewed acceptance as a continuous process. Many of the caregivers in this study referred to "just having to accept their situation", which can be construed as an attempt to avoid real emotional implications. Interviews revealed a period of pain and suffering before acceptance.

It can be concluded that patients become emotionally distressed after stroke and they deal with emotional lability, irritability, depression, anger and hopelessness. From the quotes of caregiver participants, it can also be concluded that patients do not suffer these experiences in isolation, but that caregivers also suffer the same emotional problems. The analyses cannot conclusively establish the relationship between patient's emotional state and caregiver's mental state. The interviews revealed a significant period of pain and suffering before acceptance. Hence, it can be concluded that coping with stroke involves a process that entails a number of emotional stages and that patients fluctuate between stages. It is also clear that although patients and caregivers seemed to go through some of these stages, there was a sense that each participant's progression through the stages was unique.

The conclusions prove the relevance of the ecosystems perspective as it shows how the subsystems of an individual reciprocally influence each other. These

© University of Pretoria

findings show that once the subsystem (that is the biophysical functioning of an individual) is affected, it influences the emotional and behavioural aspects of that individual as well (Hepworth et al., 2013:16).

4.3.6.2 Recommendations

- Health practitioners such as doctors and nurses should learn to recognise signs and symptoms of emotional problems, such as depression, anxiety and emotional lability, so that they can make appropriate referrals.
- Collateral information related to emotional changes experienced by patients should be obtained from caregivers.
- Health professionals working with stroke patients and caregivers should explore ways to minimise and contain the negative emotional experiences.
- Social workers must allow patients to acknowledge and mourn their losses so that necessary adaptations can be made.
- Therapist needs to be aware of different emotional reactions to stroke so that therapy can assist patients to find meaning in their experiences.
- Assessment and counselling of all stroke patients is essential to address emotional problems that patients might be experiencing.
- Counselling and support of caregivers might be beneficial to stroke patients as well.
- Further research to unravel the relationship between the patient's emotional state and caregiver's mental state is recommended.

4.3.7 Theme 6: Social consequences

4.3.7.1 Key findings and conclusions

The findings in this study indicate that social consequences of stroke that were experienced by stroke patients include disruption and revision of their relationships with their spouses, family members and the entire community. Some patients believe that their relationships were not disrupted. Relationship changes were

© University of Pretoria

mostly attributed to personality and emotional changes. Religious groups were identified as sources of support for most stroke patients and caregivers. Some mentioned that their sexual functioning has been disturbed by the stroke and this was corroborated by their spouses. They elaborated that physical limitations and emotional distress contributed to the decline in sexual activities. In terms of social participation, participants acknowledge that they suffer decreased levels of functioning and therefore their ability to participate in social activities is impaired.

It can be concluded that social the consequences of stroke entail a number of shifts in the relationship between patients and the community, their caregivers, spouse and family. It can also be concluded that there are common elements and some variations in terms of patients and caregivers' resources, such as family support and relationships. Based on this finding, religion can be identified as an important resource for stroke patients. The findings in this study indicate that patients suffer from sexual dysfunction; however, the relationship between stroke and sexual dysfunction was not fully clarified in this study.

The findings substantiate the importance of the ecosystems perspective in tapping into the social functioning of individuals. The conclusions highlight how the interpersonal systems such as family, marital, spiritual and other social networks influence each other.

4.3.7.2 Recommendations

The recommendations are aimed at improving the goodness-of-fit between the stroke patients and their caregivers, the environmental resources such as programmes, and social support systems (Hepworth et al., 2013:17).

- Social workers should assist patients and caregivers to identify and make use of appropriate resources in the community.
- Social work programmes should focus on both the psychological and social issues to facilitate delivery of holistic care to persons with stroke and their caregivers.
- Interventions should aim to strengthen social roles, social responsibilities and social involvement of patients, as well as how to link them to the wider social

© University of Pretoria

networks. Programmes to help replace lost social activities, social contacts and social roles are needed.

- Counselling should be provided to stroke patients, family members and primary caregivers to ensure that they understand the impact of stroke on the entire family network.
- Social workers should facilitate family involvement and strengthen their relationships.
- As an aspect of stroke rehabilitation, sexual activity should be routinely discussed in order to address specific needs of patients.
- Research that could conclusively establish the relationship between stroke and sexual dissatisfaction is recommended.

4.3.8 Theme 7: Greatest losses

4.3.8.1 Key findings and conclusions:

This study revealed that suffering from a stroke entails a number of losses in a variety of spheres of life, such as independence and financial stability. What emerged from the study is that patients saw mobility (both walking and driving) and financial stability as their greatest losses. Caregivers felt that the aspects that have the greatest impact on the patient are their inability to carry out daily tasks or being dependent, as well as financial instability.

It can be concluded that both stroke patients and their caregivers value independence and financial stability.

4.3.8.2 Recommendations:

The recommendation is based on the environmental approach, where the focus is on addressing losses of patients at macro, exo, meso and micro systems levels.

© University of Pretoria

- A combination of physical therapy, psychological support, and economic, and referral to social resources is essential to improve the quality of life of stroke patients.

4.3.9 Theme 8: Caregiver burden

4.3.9.1 Key findings and conclusions

This study revealed that most caregivers were coping with the practical tasks such as preparing meals, assisting patients to bath and giving them medication. Caregivers identified more problems associated with mental and physical strain. They also felt that their lives had been restricted by the stroke.

Based on the quotes of participants, it can be concluded that caregivers who live with a dependent person suffer physical, social and emotional strain. The caregiver's role is related to the severity of physical disability.

4.3.9.2 Recommendations

- Interventions should aim to increase caregivers' knowledge about patient care and mental well-being to reduce carer strain.
- To ease caregiver burden, there is a need for coordination of planned respite care, family support and arrangement for free time.
- An assessment of carer capacities and preferences should be a routine element in the management of stroke.
- There must be continuity of guidance and support for caregivers and stroke patients.

4.3.10 Theme 9: Coping strategies

4.3.10.1 Key finding and conclusion

Participants identified Christianity, patients' positive attitudes and care-skills as resources that influence positive coping.

© University of Pretoria

It can be concluded that spirituality and skills play an important role in helping caregivers to cope with the aftermath of a stroke. Participants who have knowledge about stroke and its effects cope better than those with no education about the disease.

4.3.10.2 Recommendations

- It is recommended that education and psychosocial support be provided to caregivers.
- Social workers' interventions should aim to improve and transfer skills in caring and rehabilitation.
- Caregivers' views should be included in stroke research to ensure that their issues are being addressed.

4.3.11 Theme 10: Recommendations

4.3.11.1 Key findings and conclusions

This study revealed that lack of knowledge was widely acknowledged by both patients and caregivers. Participants are not satisfied with the information received from hospitals about their illness and stroke care. They also feel that they need to adhere to treatment and should be optimistic. They recommend that caregivers must be tolerant and believe in prayer. An appeal was made to the Department of Health to procure equipment and hire permanent staff at a district level. Stroke sufferers and their caregivers need to be provided with counselling, support and education. Establishment of support groups for caregivers was recommended.

The overall recommendations emphasised the importance of the ecosystems approach, as they are aimed at enhancing the growth and adaptive capacities of individuals to overcome environmental obstacles and create more needed resources (Ross & Deverell, 2010:305).

© University of Pretoria

4.3.11.2 Recommendations for practice

Based on the recommendations of the participants, the researcher adds the following recommendations to improve service delivery:

- Social workers should be key contacts in the management of stroke care, both in the hospital and in the community. Possible social work interventions could include individual/family, couple, and group counselling and informative services.
- Integration of continuity of stroke care between hospitals and community should be established.
- In-service training of health care professionals in the protocols of acute and chronic stroke management should be done regularly.
- There should be an information system in place to record data on all services rendered to stroke patients.
- Treatment policies must address the social, physical, emotional and economic aspects of stroke. A comprehensive policy for long-term support of stroke patients that increases the accessibility of respite care should be developed.
- The social worker must possess the necessary skills regarding basic assessment and intervention, using the systemic-ecological perspective.

© University of Pretoria

5. REFERENCES

American Heart Association. 2010. The Heart and Stroke statistics 2008 update. Available: http://www.strokefoundation.org (Accessed 2012/09/10).

Anderson, R. 1992. *The Aftermath of Stroke.* London: Cambridge: University Press.

Babbie, E. 2008. *The basics of social research.* 4th ed. Belmont: Wadsworth Cengage Learning.

Bartels, M.N. 2011. Pathophysiology, medical management, and acute rehabilitation of stroke survivors. In Gillen, G. *Stroke rehabilitation: a function based approach*. 3rd ed. New York: Elsevier Mosby.

Benette, T., Grossberg, L. & Morris, M. 2005. *New Keywords: a revised vocabulary of culture and society*. Malden: Blackwell Publishing.

Besthorn, F.H. 2011. *Social work theories and methods*. New York: Columbia University Press.

Brashler, R. 2012. Social work practice and disability issues. In Gehlert, S. & Browne, T. *Handbook of health social work*. 2nd ed. New Jersey: Wiley & Sons.

Browne, T. 2012. Social work roles and health care. In Gehlert, S. & Browne, T. *Handbook of health social work*. 2nd ed. New Jersey: Wiley & Sons.

Bryer, A., Connor, M.D., Haug, P., Cheyip, B., Staub, H., Tipping, B., Duim, W. & Pinkney-Atkinson, V. 2010. South African guidelines for management of ischaemic stroke transient attack: a guideline from the South African stroke society and writing committee. *SAMJ,* 100(11):750–777.

© University of Pretoria

Conner, M. & Bryer, A. [Sa]. Stroke in South Africa: chronic disease of lifestyle from 1995–2005. Available: http://www.mrc.ac.za (Accessed 2012/09/11).

D'Alisa, S., Baudo, S., Mauro, A. & Miscio, G. 2005. How does stroke restrict participation in long-term post-stroke survivors. A*cta neurologica scandinavica,* 112:157–162.

Department of Social Development. 2014. The Draft White Paper on The Mainstreaming of the Right of Persons with Disability to Equity and Dignity. Notice 129 of 2015. *Government Gazette, 38471.* Pretoria: Government Printers.

Donoqhue, K. & Maidment, K. 2005. The ecological systems metaphor in Australia. In Nash, M., Munford, R. & Donoghue, K. *Social work theories in action*. London: Jessica Kingsley Publishers.

Edmans, J. 2010. *Occupational therapy and stroke.* 2nd ed. Malden: Blackwell Publishing.

Eisenberg, M & Rashbaum, I. 2011. Stroke. In Flanagan, S.R., Zaretsky, H. & Moroz, A. *Medical aspects of disability: a handbook for the rehabilitation profession*. New York: Springer Publishing Company.

Ekstam, L., Tham, K. & Borell, L. 2011. Couples' approaches to changes in everyday life during the first year after stroke*. Scandivian Journal of Occupational Therapy,* 18:49–58.

Eldred, C. & Sykes, C. 2008. Psychological interventions for carers of survivors of stroke: a systematic review of interventions based on psychological principles and theoretical frameworks. *British Journal of Health Psychology,* 13:563–581.

© University of Pretoria

Engstrom, M. 2012. Physical and mental health interactions, assessment and interventions. In Gehlert, S. & Browne, T. *Handbook of health social work*. 2nd ed. New Jersey: Wiley & Sons.

Falk-Kessler, J. 2011. Psychosocial aspects of stroke. In Gillen, G. *Stroke rehabilitation: a function-based approach*. 2nd ed. New York: Elsevier Mosby.

Flanagan, S.R., Zaretsky, H. & Moroz, A. 2011. *Medical aspects of disability: a handbook for the rehabilitation profession*. New York: Springer Publishing Company.

Fouché, C. 2005. An ecological understanding of social and cultural HIV practice in South Africa. In Nash, M., Munford, R. & Donoghue, K. *Social work theories in action*. London: Jessica Kingsley Publishers.

Fouché, C.B. & Delport, C.S.L. 2011. Writing the research proposal. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for social sciences and human science professions.* 4th ed. Pretoria: Van Schaik Publishers.

Fouché, C.B. & De Vos, A.S. 2011. Formal formulations. In De Vos, A.S.(Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for social sciences and human science professions.* 4th ed. Pretoria: Van Schaik Publishers.

Fouché, C.B. & Schurink, W. 2011. Quality research design. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for social sciences and human science professions.*4th ed. Pretoria: Van Schaik Publishers.

© University of Pretoria

Gardner, D.S. & Werner-Lin, A. 2012. Oncology social work. In Gehlert, S. & Browne, T. *Handbook of health social work*. 2nd ed. New Jersey: Wiley & Sons.

Gehlert, S. 2012. Communication in health care. In Gehlert, S. & Browne, T. *Handbook of health social work*. 2nd ed. New Jersey: Wiley & Sons.

Gitterman, A. & Germain, C.B. 2008. *The life model of social work practice: advances in theory & practice.* 3rd ed. New York: Columbia University Press.

Greeff, M. 2011. Information collection: interviewing. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for social sciences and human science professions.* 4th ed. Pretoria: Van Schaik Publishers.

Hartke, R.J. & King, R.B. 2003. Telephonic group intervention for older stroke carers. *Topics in stroke rehabilitation,* 9(4):65–81.

Harwood, R.H., Huwez, F. & Good, D. 2011. *Stroke care: a practical manual.* 2nd ed. New York: Oxford University Press.

Haslam, C., Holme, A., Haslam, S.A., Iyer, A.,Jetten, J. & Williams, W.H. 2008. Maintaining group memberships: social identity continuity predicts well-being after stroke. *Neuropsychological Rehabilitation,* 18(5):671–691.

Hepworth, D.H., Rooney, R.H., Rooney, G.D. & Stroom-Gottfried, K. 2013. *Direct Social Work practice: Theory and Skills.* [SI]. Brooks/Cole: Cengage Learning.

Hilari, K., Northcott, S. & Roy, P. 2010. Psychological distress after stroke and aphasia. *Clinical Rehabilitation,* 24:181–190.

© University of Pretoria

Inniss, P. 2011. Social work in physical medicine and rehabilitation. In Flanagan, S.R., Zaretsky, H. & Moroz, A. *Medical aspects of disability: a handbook for the rehabilitation profession*. New York: Springer Publishing Company.

Jack, G. 2012. Ecological perspective. In Gray, M., Midgley, J. & Webb S.A. *The sage and handbook of social work*. Los Angeles: Sage Publication.

Kengne, A.P. & Anderson, C.A. 2006. The neglected burden of stroke in sub-Saharan Africa. *International Journal of Stroke,* 1:180–190.

Kumar, R. 2011. *Research Methodology.* 3rd ed. London: Sage.

Larkin, M. 2011. *Social aspects of health, illness and healthcare.* Maidenhead: Open University Press.

Lee, Y., Chen, Y. & Hseuh, P.I. 2010. The impact of stroke: insights from patients in Taiwan. *Journal of Occupational Therapy,* 17:152–158.

Lemogoum, D., Degaute, J. & Bovet, P. 2005. Stroke prevention, treatment, rehabilitation in sub-Saharan Africa. *American Journal of Preventive Medicine,* 29(5SI):95–101.

Lezak, M.D., Howieson, D.B. & Loring, D.W. 2004. *Neuropsychological assessment*. 4th ed. New York: Oxford University Press.

Maree, K. 2007. *Qualitative research designs and data gathering techniques*. Pretoria: Van Schaik Publishers.

McCathy, M.J., Powers, L.E. & Lyons, K.S. 2011. Poststroke depression: National Association of Social Workers. *Health and Social Work,* 36(2):139.

Neuman, W.L. 2006. *Social research methods: quantitative and qualitative approaches.* 6th ed. Boston: Pearson Education, Inc.

© University of Pretoria

Niewenhuis, J. 2010a. Qualitative research design and data gathering techniques. In Maree, K. *First steps in research*. Pretoria: Van Schaik Publishers.

Niewenhuis, J. 2010b. Analysing qualitative data. In Maree, K. *First steps in research.* Pretoria: Van Schaik Publishers.

Palmer, S. & Glass, A. 2003. Family function and stroke recovery*. Rehabilitation Psychology,* 48:225–265.

Rolland, A. 2012. Families, health and illness. In Gehlert, S. & Browne, T. *Handbook of health social work*. 2nd ed*.* New Jersey : Wiley & Sons.

Ross, E. & Deverell, A. 2010. *Health illness and disability: psychosocial approaches.* 2nd ed. Pretoria: Van Schaik Publishers.

Santos, C.O., Cairo, L. & Ferro, J.M. 2006. Anger, hostility, and aggression in the first days of acute stroke*. European Journal of Neurology,* 13:351–358.

SASPI project team. 2004. Prevalence of stroke in rural South Africa. *Agincourt Field Site,* 35:627–632.

Schurink, W., Fouché, A.S. & De Vos, A.S. 2011. Qualitative data analysis and interpretation. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for social sciences and human science professions.*4th ed. Pretoria: Van Schaik Publishers.

Silwimba, P. 2013. Personal interview with Mr Peter Silwimba, Assistant Director of the Rehabilitation Programme. 10 April. Pretoria

© University of Pretoria

Stedman, T.L. 2012. *Stedman's Medical Dictionary for Health Professionals and Nursing*. 7th ed. Philadelphia: Wolters / Lippincott Williams and Wilkins.

Strydom, H. 2011a. Sampling in the quantitative paradigm. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for social sciences and human science professions.*4th ed. Pretoria: Van Schaik Publishers.

Strydom, H. 2011b. The pilot study in the quantitative paradigm. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for social sciences and human science professions.*4th ed. Pretoria: Van Schaik Publishers

Strydom, H. 2011c. Ethical aspects of research in the social science and human service professions. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for social sciences and human science professions.*4th ed. Pretoria: Van Schaik Publishers

Strydom, H. & Delport, C.S.L. 2011. Sampling and pilot study in qualitative research. In De Vos, A.S., Strydom, H. Fouché, C.B. & Delport, C.S.L. (Eds.) *Research at grass roots for the social sciences and human service professions.* Pretoria: Van Schaik Publishers.

Steyn, K. 2007. *The heart diseases in South Africa: The Heart and Stroke Foundation South Africa.* Department of Medicine: University of Cape Town.

Thomas, M. 2008. Caregivers experiences and perception of stroke. *Health S.A. Gesonheid,* 13(1):29–41.

Thompson, H & Ryan, A. 2009. The impact of stroke consequences on spousal relations from the perspective of the person with stroke. *Journal of Clinical Nursing,* 18:1803–1811.

© University of Pretoria

Wasserman S., De Villiers, L. & Bryer, A. 2009. Community-based care of stroke patients in a rural African setting. *SAMJ,* 99(8):579–583.

Wolfer, T. 2012. Religion, spirituality, health and social work. In Gehlert, S. & Browne, T. *Handbook of health social work*. 2nd ed. New Jersey: Wiley & Sons.

Zastrow, C. 2010. Introduction to social work and social welfare: empowering people10th ed. Belmont: Brookes/Cole Publishing Company.

© University of Pretoria

6. APPENDICES

6.1 Appendix A: Ethics Approval

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

27 November 2014

Dear Dr Carbonatto

Project: The experiences of patients and caregivers following a stroke
Researcher: TM Makganye
Supervisor: Dr CL Carbonatto
Department: Social Work & Criminology
Reference numbers: 11298767

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 27 November 2014. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair:Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:Karen.harris@up.ac.za

Research Ethics Committee Members: **Dr L Blokland**;Prof Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris (Acting Chair); Ms H Klopper; Dr C Panebianco-Warrens; Dr Charles Puttergill, Prof GM Spies; Dr Y Spies; Prof E Taljard; Dr P Wood

© University of Pretoria

6.2 Appendix B: Informed Consent Form - Caregivers

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work & Criminology

Researcher: Tseleng Martha Makganye

Contact details: 072 303 6741

Email: tmmakganye@ymail.com

INFORMED CONSENT FORM - CAREGIVERS

1. **Title of the study:** The experiences of patients and caregivers following a stroke
2. **Purpose of the study:** This study will explore the experiences of the patients and caregivers following a stroke. The researcher as a community based rehabilitation social worker has realised a lack of recent research related to the experiences of stroke patients and their caregivers within the South African context. It has been noted that the experiences of stroke patients has been studied in isolation, hence this current study will focus on the ecological approach which includes the experiences of both the patient and the caregiver.
3. **Procedures:** This letter serves to assist participants to make an informed consent to participate in the research. Participation is voluntary and the participant can withdraw at any time. The participant will be expected to have a 30 minutes one on one interview session with the researcher and if need arises a follow up session may be requested. The researcher will use an interview schedule which will guide the session. A voice recorder will be used with the participant's permission to record the interview. The focus and purpose of the session will be to explore the experiences of participants who are caregiving a family member following a stroke.
4. **Risks and discomfort**: The participant should note that there is a possibility that emotional discomfort may emerge because they have to discuss their personal

© University of Pretoria

experience of caregiving for a family member following a stroke. Participants who need further counselling will be referred to social workers in their clinics.

5. **Benefits:** The participant should note that there are no financial gains to be expected from this research. Participants may benefit indirectly because the study will heighten the knowledge of social workers with regard to stroke and the experiences of stroke patients and their caregivers. It will also provide guidelines for social work intervention that are in line with the needs of stroke patients and their caregivers.

6. **Participant's rights: The rights of the participant are as follows:** Participation is voluntary; no participant will be forced to take part in the research. The participant may withdraw from participation in the study at any time and without negative consequences. The participant has a right to speak out if they feel their rights are being violated

7. **Confidentiality:** Confidentiality will take highest priority, implemented as follows:

   The participant is assured that all information is treated as confidential. A number will be assigned to each participant to assure anonymity. In the event that the participant withdraws from the study, all data will be destroyed.

8. **Publication:** The findings of the research will be available in the UP library. A manuscript will be written and sent for possible publication in a scientific journal.

9. **Data storage:** The collected data will be stored for 15 years in the Department of Social Work and Criminology, according to the policy of the University of Pretoria and, when necessary, may be used for future research.

TM Makganye

Researcher

Declaration

I, ---------- understand my rights as a research participant and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being conducted.

© University of Pretoria

----------	----------	----------
Date	Place	Participant's signature
----------	----------	----------
Date	Place	Researcher's signature

© University of Pretoria

6.3 Appendix C: Interview Schedules

Interview schedule for stroke patients

Research for MSW (Health Care)

Principle Investigator: TM Makganye (11298767)

The experiences of patients and caregivers following a stroke.

1. Biographical information

1.1 Age of participant
1.2 Gender of participant
1.3 Area where participant lives
1.4 Marital status of participant
1.5 Dependent children and ages of children
1.6 Employment of participant
1.7 Composition of household

2. Stroke

2.1 Warning signs experienced before stroke diagnosis was made
2.2 Period of living with a stroke
2.3 Current treatment
2.4 Participants' understanding of disease

3. Individual (physical, emotional, social, economic, spiritual aspects)

3.1 Physical changes experienced after stroke
3.2 Any medical conditions that started after stroke
3.3 Changes in personality experienced by patient
3.4 Feelings at the time of diagnosis
3.5 Current feelings
3.6 Changes experienced by patient with regard to spiritual aspect
3.7 Changes in activities of daily living, such as house work, self-care, leisure activities
3.8 Impact of the disease on financial status (medical treatment, travelling, return to work)
3.9 Changes with regard to self-image
3.10 What are the greatest losses

4. Family

4.1 Changes in relationships with family members
4.2 Changes in relationship with the primary caregiver
4.3 Any role changes experienced

5. Society

5.1 Changes experienced as a community member
5.2 Support received from community
5.3 Attitude of service providers

6. Recommendations

Recommendations to other stroke patients, to caregivers and to service providers

© University of Pretoria

Interview schedule for caregivers

1. **Biographical information**
   Age
   Relation to stroke patient
   Economic status
   Area where participant lives

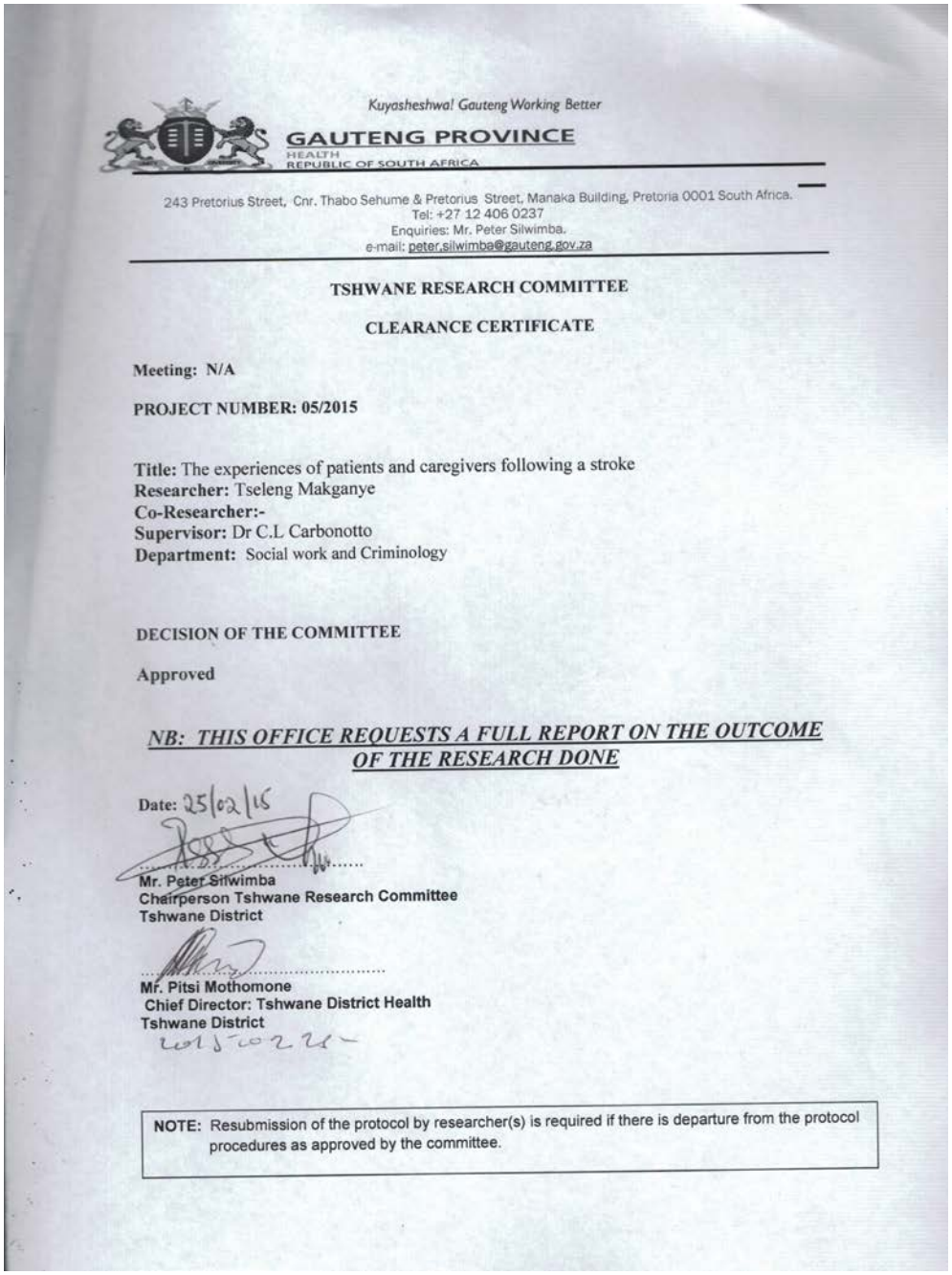
2. **General information on stroke**
   Understanding of the disease
   Period of caregiving since the onset of stroke

3. **Experience of being a caregiver**
   Expected day-to-day tasks
   Any role changes or role reversals
   Financial changes or occupational changes experienced
   Health problems experienced
   Relationship with stroke patient before stroke
   Relationship after stroke
   Altered social life
   Feelings about the whole situation
   Coping strategies
   Support from community and other family members

4. **Recommendations**
   Recommendations to other caregivers, to stroke patients and to service providers

© University of Pretoria

6.4 Appendix D: Clearance Certificate



Kuyasheshwa! Gauteng Working Better

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

243 Pretorius Street, Cnr. Thabo Sehume & Pretorius Street, Manaka Building, Pretoria 0001 South Africa.
Tel: +27 12 406 0237
Enquiries: Mr. Peter Silwimba.
e-mail: peter.silwimba@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE

CLEARANCE CERTIFICATE

Meeting: N/A

PROJECT NUMBER: 05/2015

Title: The experiences of patients and caregivers following a stroke
Researcher: Tseleng Makganye
Co-Researcher:-
Supervisor: Dr C.L Carbonotto
Department: Social work and Criminology

DECISION OF THE COMMITTEE

Approved

NB: THIS OFFICE REQUESTS A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE

Date: 25/02/15

.....
Mr. Peter Silwimba
Chairperson Tshwane Research Committee
Tshwane District

.....
Mr. Pitsi Mothomone
Chief Director: Tshwane District Health
Tshwane District
2015-02-26

NOTE: Resubmission of the protocol by researcher(s) is required if there is departure from the protocol procedures as approved by the committee.

© University of Pretoria