PERCEPTIONS OF HEALTHCARE PROFESSIONALS AND STROKE PATIENTS REGARDING SELF-MANAGEMENT.

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KEYWORDS

Stroke

Self-management

Self-management programme

Physiotherapy

Rehabilitation

Perceptions

Activity limitation

Participation restriction

Western Cape

South Africa

Health Care Professionals

Stroke Survivors

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ABSTRACT

BACKGROUND: Stroke is one of the leading causes of death and disability in the world. Stroke patients often place significant cost on the health care systems, due to long periods of care. Health care professionals play a key role in self-management as they work closely with stroke patients and patients can give insight into outcomes and during and post rehabilitation.

AIM: The purpose of this study was to explore the perceptions of Health Care Professionals and stroke patients in the Western Cape about self-management programmes. The perceptions of these individuals will assess whether self-management will be appropriate for a local setting.

METHODS: This study comprises two parts. Part one explored the perceptions of health care professionals using two focus group discussions; part two of the study used in-depth interviews with stroke patients to explore their perceptions. A descriptive, exploratory design within a qualitative research approach was used for both parts of the study. The study population for part one of the study consisted of the Health Care Professionals involved in the rehabilitation process. For part two, stroke patients admitted to Booth Memorial Hospital at the time of the study comprised the population of the study. An interview guide based on literature was used for both the focus group discussions and in-depth interviews.

RESULTS: Parts one and two of the study produced many themes that gave the researcher insight into the participants' views of the questions posed. Themes that emerged regarding the participants' views/perceptions of self-management were: independence, which included taking responsibility for their condition, regaining the ability to conduct activities and being independent, not having to depend on others and accepting help from others; and psychological factors. The health care practitioners and stroke patients did not have a clear idea of what self-management was, but did name some main aspects of the concept of self-management. The themes that emerged

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regarding whether participants felt that self-management could work when implemented into a rehabilitation programme and whether it would work in a South African setting included perceived barriers such as government resources for rehabilitation; South Africa's diverse culture and socio economic background; dependence on health care professionals; and motivation and promotion of self-confidence. The participants felt that a stroke self-management programme would be beneficial when included in a rehabilitation programme, but found that some barriers would arise in a more local context.

CONCLUSION: The study revealed that health care professionals and stroke patients in the Western Cape had a basic idea of what self-management entailed; they thought that a stroke self-management programme could work when implemented in a rehabilitation as well as a local setting, but that there are various barriers that could affect effective implementation. The current thesis informs further.

KEYWORDS: Self-management, Rehabilitation, Western Cape, Stroke

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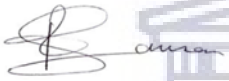
DECLARATION

I hereby declare that "Perceptions of healthcare professionals and stroke patients regarding self-management" is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources used or quoted have been indicated and acknowledged by complete references.

Renée **Jansen**



Signature……..... **2020**

Witness:

Professor Anthea Rhoda

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DEDICATION

I dedicate this thesis to my husband Roscoe for his love, patience and support. You have shown me what real strength is.

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All praise and glory to Father God for providing me with strength and courage during my studies. Through His grace all things are possible.

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TABLE OF CONTENTS

TITLE PAGE i

KEYWORDS ii

ABSTRACT iii

DECLARATION v

DEDICATION vi

ACKNOWLEDGEMENTS vii

TABLE OF CONTENTS viii

LIST OF APPENDICES xiv

LIST OF TABLES xv

LIST OF ACCRONYMS xvi

CHAPTER ONE: INTRODUCTION 1

1.0 INTRODUCTION 1

1.1 BACKGROUND TO THE STUDY 1

1.2 STATEMENT OF THE PROBLEM 4

1.3 RESEARCH QUESTIONS 5

1.4 AIM OF THE STUDY 5

1.5 OBJECTIVES OF THE STUDY 5

1.6 DEFINITION OF KEY TERMS USED 6

1.7 OUTLINE OF THE CHAPTERS OF THE STUDY 6

CHAPTER TWO: LITERATURE REVIEW 8

2.0 INTRODUCTION 8

2.1 Stroke: Definition, Epidemiology, Mortality and Prevalence 8

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

2.1.1 Definition and Diagnosis of stroke …… 8

2.1.2 Epidemiology…… 9

2.1.2.1 Incidence, Prevalence and Mortality …….. 9

2.2 Post Stroke Disability …… 12

2.3 Stroke Rehabilitation …….. 15

2.3.1 The Structure of Stroke Rehabilitation ……. ...16

2.3.2 The Processes of Stroke Rehabilitation ……....17

2.3.3 The Outcomes and Benefits of Stroke Rehabilitation ...……...18

2.4 Self-management ……19

2.5 The role of self-management programmes in long-term conditions ……...…21

2.5.1 Systematic reviews of self-management strategies in stroke …….. 22

2.5.1.1 "Self-management: a systematic review of the outcome measures adopted in self-management interventions for stroke" (Boger, Demain & Latter, 2012)... 22

2.5.1.2 "Experiences of self-management support following a stroke: A meta-review of qualitative systematic reviews" (Pearce et al., 2015)……... 22

2.5.1.3 "Self-management support interventions for stroke survivors: A systematic meta review" (Parke et al., 2015) ……..….. 23

2.5.1.4 "Self-efficacy and self-management after stroke: a systematic review." (Jones & Riazi, 2011) ……..……. 23

2.5.2 Commonly used self-management programmes ……..24

2.5.2.1 The Bridges Self-Management Programme …….……..... 24

2.5.2.2 The myMoves Program ……..... 25

2.5.2.3 Arthritis Self-Management Programs (ASMP) ……...…..… 26

2.5.2.4 Diabetes Self-Management Education (DSME) Programs ……..…… 28

http://etd.uwc.ac.za/

2.6 Perceptions and Experiences of HCP and Patients with Self-management …….. 29

2.6.1 The Perception of Self-management ……29

2.6.2 Rehabilitation and rehabilitation services ……30

2.6.3 Perception of life post stroke ……31

2.7 Summary of Literature Review ……31

CHAPTER THREE: METHODOLOGY ……..……..…… 32

3.0 INTRODUCTION ……..……..…… 32

3.1 STUDY SETTING ……..…… 32

3.2 STUDY DESIGN ……...……...….. 34

3.3 PART ONE – FOCUS GROUP DISCUSSIONS ……..... 35

3.3.1 Study population and sampling ……. 35

3.3.1.1 Study Population …… 35

3.3.1.2 Study Sample ……. 35

3.3.1.3 Inclusion and exclusion criteria ……. 36

3.3.2 Study instrument used ……... 36

3.3.2.1 Interview guide …….. 36

3.3.3 Data Collection ……...….. 36

3.3.3.1 Data collection methods ……..... 36

3.3.3.2 Data collection procedure …….. 37

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

3.3.4 Qualitative data Analysis …… 37

3.4 PART 2 – IN-DEPTH INTERVIEWS ……...…38

3.4.1 Study population and sampling …….……. 38

3.4.1.1 Study Population ……. 38

3.4.1.2 Study Sample …….…….…. 38

3.4.1.3 Inclusion and exclusion criteria……..…….…. 39

3.4.2 Study instrument used …… 39

3.4.3 Data Collection ……..…… 40

3.4.3.1 Data collection methods ……..…….. 40

3.4.3.2 Procedure ……..……. 40

3.5 QUALITATIVE DATA ANALYSIS ……..…… 41

3.6 TRUSTWORTHINESS OF QUALITATIVE DATA ……. 42

3.7 ETHICAL CONSIDERATIONS ……. 42

3.8 SUMMARY OF THE CHAPTER ……..…. 43

CHAPTER 4: QUALITATIVE RESULTS OF PART ONE AND PART TWO OF THE STUDY ……. 45

4.0 INTRODUCTION ……..……. 45

4.1 PART 1 OF THE STUDY - THE QUALITATIVE RESULTS OF THE FOCUS GROUP DISCUSSIONS ……..…… 46

4.1.1 Description of focus group …….……...…… 46

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

4.1.2 FGD results ……... 47

4.1.2.1 Participants' understanding of self-management ……..……. 47

4.1.2.1.1 Taking responsibility for the management of their condition ……. 47

4.1.2.1.2 Not Being Dependent on others ……..…. 48

4.1.2.1.3 Regaining the ability to conduct activities …….. 49

4.1.2.2 Participants' views on whether a self-management program will work in a local (South African) setting/context …….. 49

4.1.2.2.1 Government Resources for Rehabilitation …….. 50

4.1.2.2.2 Motivates and promotes self-confidence ……. 51

4.1.2.2.3 South Africa's diverse culture and socioeconomic background …. 51

4.1.2.2.4 Dependence on health care professionals …… 52

4.2 PART 2 OF THE STUDY – THE QUALITATIVE RESULTS OF THE IN-DEPTH INTERVIEWS …… 52

4.2.1 Description of the participants ……..……. 52

4.2.2 In-depth interview results ……... 53

4.2.2.1 Participants' understanding of self-management ……...……. 53

4.2.2.1.1 Being independent …… 54

4.2.2.1.2 Accepting assistance from others ……. 54

4.2.2.1.3 Psychological factors …… 55

4.2.2.2 Participants' views on whether a self-management programme will work in a local (South African) Context ..……... 56

4.2.2.2.1 Providing guidelines to recovery ……...……. 56

4.2.2.2.2 Aiding in adapting to life post stroke …….....…. 57

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

4.2.2.2.3 Assist in taking ownership of their condition ……..... 58

CHAPTER 5: DISCUSSION OF THE RESULTS OF FGD AND THE IN-DEPTH INTERVIEWS ……..…… 60

5.0 INTRODUCTION …… 60

5.1 THE PARTICIPANTS' PERCEPTIONS OF SELF-MANAGEMENT ……. 60

5.1.1 Independence ……. 61

5.1.1.1 Taking Responsibility for their condition …… 61

5.1.1.2 Regaining the ability to conduct activities and being independent ……..62

5.1.1.3 Not having to depend on others and accepting help from others .....…63

5.1.2 Psychological Factors …….…….65

5.2 THE PARTICIPANTS' VIEWS ON WHETHER A SELF-MANAGEMENT PROGRAMME IS APPROPRIATE IN A LOCAL (SOUTH AFRICAN) SETTING/CONTEXT ……. 66

5.2.1 The HCPs' and patients' views on whether a self-management program could work in a local (South African) setting/context …… 66

5.2.1.1 Possible barriers to the implementation of a SMP ……..…. 66

5.2.2 Implementation of a SMP as part of a rehabilitation program …… 68

CHAPTER 6: SUMMARY, LIMITATIONS, CONCLUSION, SIGNIFICANCE OF THE STUDY AND RECOMMENDATIONS ……..…… 70

6.0 INTRODUCTION ……70

6.1 SUMMARY OF THE STUDY……..…… 70

6.2 LIMITATIONS OF THE STUDY ……..…… 71

6.3 CONCLUSION ……..….... 71

6.4 SIGNIFICANCE OF THE STUDY……..…… 72

http://etd.uwc.ac.za/

6.5 RECOMMENDATIONS ……...…… 72

REFERENCES ……..…… 74

LIST OF APPENDICES

APPENDIX 1: Information Sheet: Healthcare Professionals ……. …….……94

APPENDIX 2: Information Sheet: Stroke Patients ……..… 97

APPENDIX 3: Afrikaans Information Sheet: Stroke Patients…..……. 100

APPENDIX 4: Focus Group Confidentiality Binding Form …… 103

APPENDIX 5: English Consent Form- Stroke Patients ……..... 104

APPENDIX 6: Afrikaans Consent Form: Stroke Patients ……. 105

APPENDIX 7: Consent Form: Health Care Professionals – Focus Group …… 107

APPENDIX 8: Focus Group Discussion Guide for Health Care Professionals …….108

Appendix 9: English Interview Guide for Stroke Patients ……..109

Appendix 10: Afrikaans Interview Guide for Stroke Patients …….110

Appendix 11: Ethics Approval Letter …….111

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

LIST OF TABLES

Table 3.1: Classification of severity ……. 39

Table 4.1; Focus group participants ……..… 46

Table 4.2: Themes, categories' and code for Participants' understanding of self-management – FGD ……..……..…… 47

Table 4.3: Themes, categories and codes for Participants' views on whether a self-management program will work in a local (South African) setting/context – FGD…… 49

Table 4.4: Distribution of the interview participants ……..... 53

Table 4.5: Themes, Categories and Codes for Participants' understanding of self-management – In-depth interviews……. 53

Table 4.6: Themes, Categories and Codes for Participants' views on whether a self-management programme could work in a local (South African) context – in-depth interviews ……..….56

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WESTERN CAPE

http://etd.uwc.ac.za/

LIST OF ACRONYMS

ADL(s)	Activities of Daily Living
ASMP	Arthritis Self-Management Program
CVA	Cerebral Vascular Accident
DOH	Department of Health
DSME	Diabetes Self-Management Education
FDG	Focus group discussion
HCP	Health Care Professional
MDT	Multi-disciplinary team
SM	Self – management
SMP	Self-management program
SPO	Structure, Process and Outcome (framework)
StatsSA	Statistics South Africa
TIA	Transient Ischemic Attack
UNECE	United Nations Economic Commission for Europe
WGDS	Washington Group Disability Statistics

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CHAPTER 1: INTRODUCTION

1.0 INTRODUCTION

This chapter outlines the background of the study, presents the burden of stroke and the resulting disability post stroke, the role of rehabilitation and the role of health care providers. It further presents the burden of stroke patients have on the health system and, lastly, the role self-management can play in rehabilitation. It goes onto explain the rationale of the study and introduce the problem statement, the research question, the aim and the objectives of the study. The key terms used in the study are defined and a brief outline of the chapters of the study is presented.

1.1 BACKGROUND OF STUDY

Stroke is one of the foremost causes of death in the world (Kuptniratsaikul, Kovinhda, Suethanapornkul, Manimmanakorn & Archongka, 2013). It is a life changing event that has a significant impact on many aspects of the life of stroke survivors and their families (Ahuja, Clark, Morahan, ONO, Mulligan & Hale, 2013). In developing countries, the prevalence of stroke continues to grow (Feigin, Lawes, Bennet, Barker-Collo & Parag, 2009) and 5.5 million deaths worldwide were due to cerebrovascular disease with 2.8 million deaths from hemorrhagic stroke and 2.7 million deaths from ischemic stroke in 2016 (Benjamin, et al., 2019). Stroke is responsible for up to 25 000 deaths in South Africa yearly (Benjamin et al., 2016) compared to the incidence in New Zealand where up to 6000 new strokes are registered per year (Brown, 2009) and stroke remains the most complex and the most common cause of complex disability in the UK, with around 32,000 stroke-related deaths annually (Public Health England & Steve Brine, 2018). In the United States, 130,000 Americans die as the result of a stroke almost yearly (Kochanek, Xu, Murphy, Miniño & Kung, 2011), while more than 50,000 people in Canada experience a stroke

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every year and more than 300,000 currently live with the resulting impairments (Lindsay et al., 2008).

Desrosiers et al. (2006) state that, although patients experience some form of disability post stroke, they still have to face the task of reintegrating back into their community. Stroke is one of the main causes of disability (Ntamo, Buso & Longo-Mbenza, 2013) and its effects are often catastrophic for the patient and their families (Hassan, Visagie & Mji, 2011).

The International Classification of Functioning, Disability and Health Framework describe disability in terms of impairments, activity limitations and participation restrictions, which takes into account contextual factors (WHO, 2004). Impairments resulting from stoke often include one or more of the following: sensory fallout, visual fallouts, cognitive impairments, bladder and bowel incontinence, speech and language fallout, personality changes, swallowing problems and paralysis or weakness of limbs (Stroke Association, 2006; Tipping, 2008). Activity limitations post stroke include basic Activities of daily living (ADLs) including, but not limited to, mobility, transfers, toileting, feeding and bathing (Stroke Association, 2006; Urimubenshi, 2015). Participation restrictions post stroke refer to the roles they fulfilled prior to the stroke (WHO, 2004), such as returning to prior employment, partaking in leisure activities and the incapability of participating in religious activities (Desrosiers et al., 2006; Urimubenshi, 2015). Rehabilitation interventions are needed to address the functional limitations experienced by patients with stroke.

Rehabilitation post stroke plays a key role in the re-acquisition of function (Ntamo et al., 2013; Kuptniratsaikul et al., 2013). According to Langhorne and Legg (2003), stroke rehabilitation can be defined as ‘‘a problem solving process aiming at reducing the disability and handicap resulting from a disease’’. This is the most common treatment intervention in patients with stroke. In

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promoting quality of life, its aim is to assist with functional independence and the reintegration back into their community (Van Peppen, Hendriks, Van Meeteren, Helders & Kwakkel, 2007).

The effects of stroke place a costly burden on the health system, due to long periods of care (Ntamo et al., 2013). It is therefore important that methods to decrease the burden on the health system be explored and developed. Research has shown that self-management has been linked to reduced use of the health care system and therefore decreases the cost when incorporated into rehabilitation (Gibson, 2003; Effing, 2007; Jovicic, Holroyd-Leduc & Straus, 2006). Although there are many definitions, the core of self-management "is the active engagement of the individual patient (and his /her family) to participate in the care of their own illness" (Rademakers, Jansen, van der Hoek & Rosamond, 2015). Self-management could be incorporated into a rehabilitation programme as research has shown that these programmes can play a key role in promoting recovery (Thoolen, Ridder, Bensing, Gorterm & Rutten, 2008).

Few self-management programmes have been specifically designed for stroke survivors (Jones & Brimicombe, 2014) and those that have been designed may not be applicable in a South African context. The Bridges Self-Management Programme for stroke survivors in the United Kingdom that promotes self-efficacy and involves the survivor, the health care professional and family members/care givers, may not be applicable in a South African context. Some self-efficacy programs used in a South African context are designed for other conditions such as the: Stanford Arthritis Program, developed at the Stanford Patient Education Research Center, led by Professor Kate Lorig, Dr PH and various diabetes programs based on the guidelines of the DSME in South Africa (Dube, Van den Broucke, Housiaux, D'Hoore & Rendall-Mkosi, 2015) and have had positive outcomes in a South African setting.

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Health care professionals are vital in the effective promotion of self-management post stroke (Doswell, Doswell, Lawler, Green & Young, 2002; Robinson-Smith, 2002; Western, 2007). They can guide a patient's motivation and eventually the patient's preservation of beneficial health behaviors, by using their communication style and implementation of a patient-centered approach (Ng et al., 2012). Several interventions across different populations have shown that the application of self-management principles can promote a patients' active role in managing their illness (Jones & Riazi, 2011).

Healthcare professionals and patients could provide valuable feedback on the rehabilitation interventions, it therefore is imperative to consider their views (Hewlett, 2000; DOH, 2000; Sadler, Wolfe, Jones & McKevitt, 2014). Although these opinions are important, there is not much data that emphasise the views/perceptions of stroke survivors (Satink, Cup, De Swart & Nijhuis -van der Sanden, 2015; Boger, Demain & Latter, 2015) and health care professionals regarding self-management. It is therefore important to further explore the perceptions and views of self-management.

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1.2 STATEMENT OF THE PROBLEM

Due to a lack of resources, rehabilitation services for disabled patients in South Africa are limited, (Kumurenzi et al., 2015). Research has shown that self-management, when incorporated with rehabilitation, has been associated with less use of the health care system hence decreasing the cost/financial burden. Self-management support has also been shown to facilitate improved functional outcomes of patients with stroke (Parke et al., 2015). Self-management programmes are therefore ideal in situations where rehabilitation or health services are lacking.

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However, no self-management programmes applicable to the stroke population are available in developing countries such as South Africa. Previously developed programmes could therefore be adapted (Jones, 2006) and applied for the local setting.

The views from both the HCP and patients are key, however, when planning and adapting rehabilitation programme (Nordin et al., 2014), as these views will provide a rich source of information to shape, implement and adapt these programmes better. There thus is a need for exploring the perceptions of HCPs and stroke patients about self-management when adapting these programmes for a local setting.

1.3 RESEARCH QUESTION

What are the South African HCPs' and stroke patient's perceptions about self-management?

1.4 AIM OF THE STUDY

To explore the perceptions of Health Care Professionals (HCPs) and stroke patients in the Western Cape about self-management.

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1.5 OBJECTIVES OF THE STUDY

1.5.1 To explore the understanding of HCPs and stroke patients of the concept of self-management.

1.5.2 To explore the HCP perceptions of the application of self-management strategies by stroke survivors.

1.5.3 To explore HCP and stroke patients' perceptions regarding the integration of self-management strategies into current rehabilitation programmes.

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1.6 DEFINITIONS OF KEY TERMS USED

Local setting: For the purpose of this study, South Africa.

Perception: The way in which something is regarded, understood, or interpreted. Cambridge English Dictionary, online.

Self-management: "active management by individuals of their treatment, symptoms, lifestyle, physical and psychological consequences inherent with living with a chronic condition" (Lorig & Holman, 2003).

Stroke: "rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin" (WHO-MONICA Project, 1988).

View: Regard in a particular light or with a particular attitude (Cambridge English Dictionary).

Stroke survivors: Those who have survived a stroke and now live with the resulting disabilities, who no longer are patients (US Agency for Health Care Research and Quality, 1995).

Stroke Rehabilitation: It is a process whereby people who have suffered a stroke, attempt to regain maximal function post the event and integration back into the community; this is a goal-orientated process that focuses on the survivors' cognitive skill, language fallout and physical disabilities (Bryer et al., 2010).

1.7 OUTLINES OF THE CHAPTERS OF THE STUDY

Chapter 1 describes the foundation of this study. It begins with a depiction of the background of the current study, in which the lack of resources for rehabilitation services is limited in South Africa. It is followed by the problem statement, research questions, aim and objectives of the study. The chapter then ends with the definitions of terms used in the study.

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Chapter 2 of the thesis presents the literature review, which includes the definition of a stroke and its types, the impact of stroke in South Africa, as well as the epidemiology of stroke, including its incidence, mortality and prevalence. It continues with the disability resulting from a stroke and the role of self-management in long-term conditions. The chapter concludes with a discussion of the role of self-management in stroke rehabilitation.

Chapter 3 describes the methodology used in this study. This includes the two parts of the study; the study setting, study design and the study population are described. Moreover, other methodological topics such as the study instrument, the procedure of data collection for both parts of the study and analysis are described. Then, finally, the ethical considerations adhered to during the completion of the study are explained.

Chapter 4 offers a discussion and presents the qualitative results of part 1, the focus group discussions in relation to the categories and themes that emerged. The discussion focuses on the interpretation of the study findings and a comparison with other similar studies outcomes.

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In Chapter 5, the qualitative results of part 2 of the study, the in-depth interviews, are discussed and presented in relation to the categories and themes that emerged. The discussion also focuses on the interpretation of the study findings and a comparison with other similar studies.

The final chapter presents a summary of the study, its limitations and conclusions, the significance of the study and recommendations for further exploration.

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CHAPTER 2:

LITERATURE REVIEW

2.0 INTRODUCTION

In this chapter, the literature with regard to stroke, its epidemiology and its impact in South Africa is discussed. Presented furthermore, is a discussion of the disability caused by stroke, stroke rehabilitation, self-management and the role of self-management under long-term conditions. The literature review concludes with the pointing out the importance of patients' views and the perceptions of health care professionals and patients relating to rehabilitation. Finally, there is a general summary of the literature.

2.1 STROKE: DEFINITION, EPIDEMIOLOGY, MORTALITY AND PREVALENCE

2.1.1 Definition and Diagnosis of stroke

The World Health Organization (WHO) defines stroke as "a focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 hours (or leading to death), and of presumed vascular origin" (WHO, 2004). The two main types of strokes are the ischemic stroke and a cerebral hemorrhage (hemorrhagic). Ischemic stroke is usually caused by an embolus or thrombus that results in a blockage (Bryer et al., 2010). An ischemic stroke accounts for 85 percent of all strokes (Norman, Bradshaw, Schneider, Pieterse & Groenewald, 2007; Yusuf, Reddy, Ounpuu & Anand, 2001). Hemorrhagic strokes are caused by the rupture of a cerebral vessel that leads to bleeding into the brain (intra-cerebral bleed) or subarachnoid space (subarachnoid hemorrhage) (Bryer et al., 2010). This type of stroke accounts for 15 percent of all strokes (Norman et al., 2007; Yusuf et al., 2001). A minor stroke, known as a TIA (transient ischemic attack), is any cerebral

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vascular event lasting less than 24 hours and results in full recovery, although the identification is important for the implementation of measures to prevent secondary onset of an actual stroke (WHO, 1989). More recently, Easton et al. (2009) from the American Heart and Stroke Foundation, has defined a TIA as a "transient episode of neurological dysfunction caused by focal brain, spinal cord, retinal ischemia, without acute infarction".

The diagnosis of a stroke requires a proper clinical assessment, including concise medical history and a thorough clinical examination (general and neurological). When a stroke is suspected, a barrage of diagnostic tests are required; these include but are not limited to an ECG, various blood tests and brain imaging (CT Brain, MRI scan) (Bryer et al. 2010). A stroke can only be definitively diagnosed using Computerized Tomography (CT) or Magnetic Resonance Imaging (MRI), as they identify whether a hemorrhagic or ischemic stroke has taken place and the severity thereof (Bryer et al., 2010; Connor & Bryer, 2006). In developing countries not all stroke diagnoses are made using CT scans or MRI due to a lack of the availability of these machines (Kengne & Anderson, 2006).

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2.1.2 Epidemiology

Stroke epidemiology can be defined in terms of incidence, prevalence and mortality (Warlow, 1998). Although the incidence of stroke in South Africa is not widely known, data are available regarding stroke mortality and prevalence (Conner & Bryer, 2006). StatsSA (2017), observed that South Africa is currently going through an epidemiological transformation, with a definite pattern showing that there has been a shift in the causes of death over the period of 2011–2016. Initially the most common causes of death were infectious diseases, whereas it at present is moving towards non-communicable diseases, such as cardiovascular diseases, asthma and cerebrovascular diseases, including stroke.

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2.1.2.1 Incidence, Prevalence and Mortality

According to Feigin et al. (2009) one in every six individuals worldwide will experience a stroke in their life time, in accordance with the global burden of stroke. About 4 000 000 persons alive today have survived a stroke and have some neurological deficits.

In October 2007 as a part of the Joint World Congress of stroke, stroke was declared a catastrophic illness in South Africa and is ranked at number 9 in South Africa as one of the major causes of disability (Bryer et al. 2010). Each year in South Africa about 75 000 strokes occur, of those who survive 25 000 die less than 1-month post stroke (Bertram, Katzenellenbogen, Vos, Bradshaw & Hofman, 2013). At present there is a huge health transition in South Africa, that can be described by the concurrent increase of non - communicable diseases (cardiovascular disease, type 2 diabetes etc.) and the incidence of infectious diseases (Mayosi et al., 2009; Tollman et al., 2008). According to multiple studies the stroke onset in Western Cape, South Africa, is now occurring in a younger population compared to that of more developed countries, leading to these stroke survivors living longer (Connor & Bryer, 2006; Rhoda, Mpofu & De Weerdt, 2011). The high incidence of young strokes can be attributed to the high poverty cycle (drug abuse) and multiple health risks such as HIV/Aids and TB (National department of health framework and strategy for disability and rehabilitation services in SA 2015 - 2020).

Prevalence of stroke can be defined as the amount of a population affected by a stroke at a particular time. (Roger, et al., 2011). Bryer et al. (2010) suggests that the occurrence of stroke is higher in urban areas compared to rural areas, due to the fact that people in urban areas are more exposed to lifestyle risk factors. In rural South Africa however, the prevalence of incapacitating stroke is already as great as in high – income countries (Conner et al., 2006).

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The mortality rate of stroke relates to the amount of deaths caused by stroke in a particular period, commonly one year (StatsSA, 2008).

More recently statistics from StatsSA, cerebrovascular diseases ranked 7th in 2016s 20 most commonly reported causes of death and was responsible for 7.6 % deaths (StatsSA, 2017).

Johnston, Mendis & Mathers (2009) stated that Stroke affects 15 million patients worldwide each year, resulting in death and profound disability in two-thirds of the survivors and death in about one third of patients. Furthermore, Kunkel, Fitton, Burnett & Ashburn (2015) found that 73% of stroke survivors spend most of their day sitting or lying down, 3 years post stroke event. Stroke is one of the most common incapacitating diseases that have a profound impact on a person's life (Donnan, Fisher, Macleod & Davis, 2008). McKevitt, Redfern, Mold & Wolfe (2004) state that the long term impact on an individual includes physical (mobility), psychological (mood disturbances) and social aspects (communication difficulties, life roles). Statistics South Africa released data reporting that, by 2003, the number of early adult deaths, categorized from the ages 15 to 64, that resulted from stroke increased by 28% (Statistics South Africa, 2008).

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The highest mortality rate in stroke is in black females, namely 160 per 100 000, while white males had the lowest stroke mortality rate of 72 per 100 000 persons (Bryer et al., 2010). Bryer et al. (2010) also stated that deaths resulting from stroke in the black and coloured population were double that of the white population. Black African people have the lowest death rates with Indian people showing the highest rate of death (Norman et al., 2006). Leeder, Raymond and Greenberg (2004) found that, most untimely deaths among individuals aged 35-64 years old are caused by cardiovascular disease and this is likely to increase by 41% between 2000 and 2030.

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2.2 POST STROKE DISABILITY

According to the StatsSA report based on the 2011 census, in South Africa, the disability prevalence rate due to stroke is 7.5%, with disability being more prevalent in females than males (StatsSA, 2014). The report also noted that the Western Cape reported the second lowest disability level in South Africa at 5.4%, with stroke being the leading cause of disability. The disability report compiled according to census 2011 revealed that, among 11% of people over the age of 5 years old, 2% had walking and self-care difficulties, 4.2% had cognitive fallout and 3.6% had a hearing fallout. Internationally, the World Health Survey found that 15.6% of the world's population suffered from some form of disability, with cases being more prevalent in developing countries (WHO, Report on Disability). A study by the World Bank found that between 110 million and 190 million people globally suffer from severe disabilities. These difficulties impact on the individual's socioeconomic outcomes (worldbank.org).

The method of recording these global statistics has been standardized by using the Washington Group questions. In 2010 the Housing and Population Censuses – a "foundation of statistical systems, providing benchmarks of a country's population and housing baseline information for the production of other statistics" UNECE website of the United Nations Economic Commission for Europe (UNECE) – implemented a set of questions on disability that was established by the Washington Group (WG). This new and improved approach to measuring disability is based on "activity limitations and restrictions in social participation, with the aim of producing prevalence measures that are internationally comparable" (Eide & Loeb, 2005). With the backing of the UN Statistics Division, the Washington Group on Disability Statistics (WGDS) was instructed to aid in the development of general disability measures that were appropriate for use in sample-based national surveys and censuses (StatsSA, 2014). The aim of the WGDS was to identify people who

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would feel restricted during social participation because they struggle with basic activities. They based the assessment on the activities that would result in restrictions to participation. A core set of six questions involving self-care, walking, cognition, seeing, communication and hearing based on the ICF International classifications framework with a stringent focus to allow for international comparability (Madans et al., 2004).

As discussed in Chapter 1, these disabilities can be classified using the International Classification of Functioning, Disability and Health framework (ICF) (WHO, 2004). In this frame work, disability is a broad term that covers activity limitations, impairments and participation restrictions (WHO, 2004. Stroke is the most common cause of neurological disability in the western world (Roger et al., 2012; Rosamond et al., 2008). Post stroke, the resulting disabilities include worsening motor skills, falls, and urinary incontinence (Divani, Majidi, Barret, Noorbaloochi & Luft, 2011; Tipping, 2008; Rathore, Hinn, Cooper, Tyroler & Rosamond, 2002).

Activity limitations can be defined as the complications that arise when performing actions or tasks; impairments are defined as issues experienced with bodily functions and structures and participatory restrictions are tasks that individuals would encounter in everyday real-life situations (WHO, 2004:12). The ICF framework supports the fundamental addition of the contextual factors; these contextual factors combine both environmental and personal factors (WHO, 2001:12) that affect functioning post stroke. These factors allow rehabilitation interventions to be more effective within the stroke survivor's context (Loeb, Eide & Mont, 2008). This framework also includes the interaction of its five constituents, which are body functions, body structures, participation and activities, and personal and environmental factors.

Oliveira et al. (2013) further estimated that 30-40% of stroke survivors, on average, develop some degree of functional dependence and require assistance with the basic activities of daily living.

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Examples of impairments include abnormalities in muscle tone, cognitive fallouts and speech and language memory fallout (Lawrence, Coshall, Dundas, Stewart & Rudd, 2001). Commonly recognized activity limitations include, restrictions with gait and inability to autonomously execute activities of daily living (Rhoda *et al.*, 2009; Hartman-Maier, Soroker, Ring, Avni & Katz, 2007). A study conducted by Joseph and Rhoda (2013) to investigate activity limitations pre discharge from rehabilitation facilities found that, even upon discharge, stroke survivors are still unable to perform basic ADLs such as dressing and transferring, as well as mobility and negotiating stairs. Similarly, a study by Rhoda (2012) had found that stroke survivors will have increased activity limitations; participants emphasized that poor active use of the upper limb affected self-care.

Participatory restrictions experienced by stroke survivors can be defined as the inability to perform familial duties, go back to work and poor participation in leisure activities (Daniel, Wolf, Busch & McKevitt, 2009). If the impairments and activity limitations are not addressed, complications relating to the participation of stroke survivors in their daily lives and interactions with their community may arise post discharge (Mayo et al., 2002).

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These activity limitations and participatory restrictions impact individuals in various ways. A qualitative study by Rhoda (2012), found that patients experienced limitations with mobility (making use of public transport or driving and walking) and self-care (independent dressing and bathing). The study further mentioned participatory restrictions including an impact on work and employment, interpersonal relationships, domestic life (assisting others and maintenance of household objects) and recreational and leisure activities (Rhoda, 2012). Cawood, Visagie and Mji (2016) similarly found that mobility in their home and around their community, including climbing stairs and toileting as activity limitations, and the study listed participatory restrictions in many areas – including sport, leisure and employment activities. Kuys, Bew, Lynch and Brauer (2014)

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listed basic activity limitations experienced by stroke survivors such as bed mobility and sitting balance.

Langhorne and Legg (2003) have found that, due to the disabilities caused by stroke, stroke rehabilitation is necessary. Post stroke rehabilitation has been proven to be advantageous in the recovery process and has been successful in improving quality of life (Mendis, 2013; Milinaviciene, Rastenyte & Krisciunas, 2007).

2.3 STROKE REHABILITATION

In the South African context, the South African guideline for the management of stroke and transient ischemic attack (2010) defines stroke rehabilitation as "a goal-orientated process which attempts to obtain maximum function in patients who have had strokes and who suffer from a combination of physical, cognitive and language disabilities" (Arowoiya, 2014). Dobkin (2001), states that post stroke rehabilitation should continue to address severe functional limitations, in order to limit further disability. In South Africa however, not all stroke survivors are referred for any type of rehabilitation (Wasserman, De Villiers & Bryer, 2009). According to Bryer *et al.* (2010), the "ultimate goal of rehabilitation" is for stroke survivors to recommence pre stroke function relating to participation in both community and family life and that alternative approaches should be explored if the above is not possible.

The Structure, Process and Outcome (SPO) framework is used in rehabilitation research in order to reduce the complexity of rehabilitation research (Hoenig et al., 2002). This framework was originally developed as tool in order to assess the quality of care. The frame work refers to the structure, which is the organizational and physical characteristics where care is provided; the processes, which focus on the referral processes, content of care received and the type of services

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the patients receive; finally, the outcome, which can be measured by the characteristics in a patient that have changed due to the care received (Hoenig et al., 2002). This section is further discussed in terms of the SPO framework.

2.3.1 The Structure of Stroke Rehabilitation

The many clinical presentations of stroke are complex; because of this, the best form of implementation is a client-centered interdisciplinary rehabilitation team approach (Page, Levine, Sisto, Bond & Johnston, 2002; Stroke Unit Trialists' Collaboration, 1997; Bryer et al., 2010). An interdisciplinary rehabilitation team often is comprised of many rehabilitation professionals including a physiotherapist, psychologist, occupational therapist, social worker, a speech and language therapist, rehabilitation nurses, medical doctor and dietician (Bryer et al., 2010; Shah, Vanclay & Cooper, 1989). A study by Cawood and Visagie (2016) at a rehabilitation facility in the Western Cape found that physiotherapy was the most common intervention during admission, followed closely by occupational therapy. However, there was limited involvement by other members of the team, such as speech therapists, dieticians and social workers.

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Depending on the stage of rehabilitation during the course of stroke, services are offered at different settings or levels of care (Chimatiro, 2012). These settings include out-patient and community-based rehab, and institutionalized-based rehabilitation. (Rhoda et al., 2009; Ottenbacher & Graham, 2007). Stroke rehabilitation usually starts in an acute care hospital setting. Then, if needed, it progresses to a more structured rehabilitation service such as a sub-acute or step-down facility to address remaining impairments. Once these patients are discharged, they then return to the community (Page et al., 2002). The average length of stay in a tertiary hospital in South Africa for stroke patients is 10.4 days (Parekh & Rhoda, 2013) and 8 days in a District Hospital (Bryer et al, 2010) in the Western Cape. There is little time for treatment and adjustment

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of resulting impairments post stroke, education about compensatory strategies and family training pre-discharge due to short hospital stays (Cawood & Visagie, 2016).

2.3.2 The Processes of Stroke Rehabilitation

The process of stroke rehabilitation usually involves an assessment, realistic goal setting, intervention planning and, lastly, reassessment of the situation, in order to assess progress and maintain alignment with preset goals (Langhorne, Bernhardt & Kwakkel, 2011). There are three phases of stroke rehabilitation: an acute phase, the first few weeks post stroke, when the patient is stabilized; the sub-acute phase (1-6 months); the most effective rehabilitation phase – most function recovery happens in this phase – and finally the chronic phase (after 6 months). In this phase the aim of rehabilitation is to assess and treat motor fallouts in order to decrease further disability (Aqueveque et al., 2017). There is huge consensus in literature that rehabilitation should start as soon as possible post stroke (Bryer et al, 2010; Bernhardt, Thuy, Collier & Legg, 2009). Kwakkel, Kollen and Lindeman (2004) suggest that rehabilitation interventions work better when adjusted to the appropriate phase.

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Stroke rehabilitation interventions are usually multifaceted and often contain numerous organized components (Craig et al., 2008). Some of these interventions include cognitive rehabilitation interventions; early supported discharge services; outpatient rehabilitation services; therapy-based rehabilitation services; ankle-foot orthosis; behavioral therapies for urinary incontinence; rhythmic gait cueing; motor learning or movement science; and seating and positioning policies, to name but a few (Langhorne et al., 2011).

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2.3.3 The Outcomes and Benefits of Stroke Rehabilitation

Mamabolo, Mudzi, Stewart, Olurunji and Singh (2009) found that stroke patients upon discharge still have limited functional independence and community-based rehabilitation services often are either inadequate or inaccessible (Rhoda & Hendry, 2006). Due to these circumstances, stroke patients often struggle to reintegrate back into family life and their community (Midwest Nursing Research Society, 2001). In line with this increasing demand for rehabilitation services, it is important that all stake holders find the most "effective, efficient and acceptable methods of managing stroke patients" (Anderson et al., 2000).

There is mounting evidence that rehabilitation post stroke can greatly benefit stroke patients (Duncan et al., 2002; Whitehead & Baalbergen, 2019). A meta-analysis by Legg and Langhorne (2004) offered proof that continued rehabilitation input post discharge led to a decreased risk of further disability and improvement of participation in activities of daily living in stroke survivors. Many exceptional benefits of different multi-disciplinary rehabilitation interventions have been shown to address the various long term results following a stroke (Langhorne & Holmqvist, 2007; Langhorne, Bernhardt & Kwakkel, 2011; Pinter & Brainin, 2012). These benefits include improvement of ADLs, shorter hospital stays (Langhorne & Holmqvist, 2007; Forster, et al., 2009). Additionally, the guidelines set out by the American heart and stroke associations for adult stroke rehabilitation and recovery state that a comprehensive rehabilitation programme, which includes the correct duration, dose and sufficient resources are essential post stroke (Mozaffarian, et al., 2016). Furthermore, a Cochrane systematic review by Pollock et al. (2014), found that rehabilitation is effective in the recovery of mobility and function, post stroke.

There is a growing demand on rehabilitative services, Stucki, Cieza and Melvin (2007) suggest that self-management strategies employed by people with long-standing diseases, like stroke and

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its resulting disabilities, can help decrease these demands. However, self-management strategies have only recently been adapted for stroke survivors (Jones & Riazi, 2011).

2.4 SELF-MANAGEMENT

There are many definitions for and opinions on self-management. As early as 1988, Nakagawa-Kogan *et al*. (1988) defined self-management as a treatment that combines biological, psychological and social intervention techniques with an end goal of maximal functioning. A review by Clark, Becker and Janz in 1991, suggests that authors, in general, interpret self-management as daily tasks that an individual must undertake to control or reduce the impact of disease on one's physical health. These tasks are undertaken with the guidance of the individual's physician and other health professionals. More recently Effing (2007) and Jovicic (2006) defined self-management as an active participation of the patient and his/her family in the care of their own illness. This involves medical aspects, coping with the illness and associated problems in daily life. A recent study by Van de Velde et al. (2019), noted that self- management is a complex concept. The authors felt that further studies were needed to make the concept of self-management more measurable.

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There is a very necessary need for the relationship roles between professionals and patients to change and a definite need for a "huge shift in power dynamics" in this relationship (Audulv, Asplund & Norbergh, 2010). Despite the developing evidence supporting self- management, much support and training is still essential in order improve health care professionals' behaviors, skills and approaches regarding self-management (Kosmala-Anderson, Wallace & Turner, 2010; Hibbard, Collins, Mahoney & Baker, 2010).

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According to Bodenheimer, MacGregor and Shafiri (2005), there are two ways of viewing self-management support: an essential conversion and change to a shared partnership from the existing stroke survivor-caregiver relationship; and as an assortment of tools and practices to assist stroke survivors to make healthy choices regarding their wellbeing (De Silva, 2011). Giving patients the necessary skills and knowledge to set goals, build confidence and cultivate effective strategies to achieve these goals, are the main focus in multiple self-management interventions (Yip *et al.,* 2007; Sturt. Taylor, Docherty, Dale & Louise, 2006; Samoocha, Bruinvels, Elbers, Anema & Van der Beek, 2010; Greenhalgh et al., 2010).

Barlow, Turner & Wright (1998). suggest that self-management might be a way to bridge the gap between patients' needs and the ability of health and social care services to meet those needs. Mendis (2013) stated that there is strong evidence that the promotion of individual empowerment for self-management is very effective in the management of chronic diseases. Furthermore, De Silva (2011) had also reported that there is overwhelming proof that self-management support can affect an individual's knowledge about their condition, clinical and quality of life outcomes and self-efficacy. Parke et al. (2015) however, state that, although elements of self-management are successfully provided by rehabilitative therapy, the exact self-management terminology is not often used in the context of stroke. Recently, multiple new methods of helpful ways of transitioning and adjusting post stroke have been suggested, including the addition of self-management programmes (Cadilhac et al., 2011).

Some well-known self-management strategies are explored in the next section.

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2.5 THE ROLE OF SELF-MANAGEMENT PROGRAMMES IN LONG-TERM CONDITIONS

There is growing consensus in the western world that patients should be active participants in the management of their own healthcare and it was recommended that patients' care plans be individualized (Rademakers, 2015). The methodology on which self-management is based was initially developed in 1989 for the treatment of smokers by the National Cancer Institute. This methodology can therefore be applied to patients affected by stroke (Morais, Gonzaga, Aquino & Araujo, 2015). Furthermore, Adams et al. (2004) have stated that ideas around active backing of self-management were initially applied with assistance in the management of arthritis. Ham et al. (2012) state that self-management programmes are considered to be among the top priorities in rehabilitation and health care. In 2007 the UK National Stroke Strategy, encouraged self-management initiatives to address unmet needs and that all patients be offered self-management training. De Silva et al. (2011) proposed that "self-management programs are designed to provide people with the information skills and support they need to effectively manage their condition".

Systematic reviews have shown that self-management principles are often employed in rehabilitation programmes, but that researchers do not specifically use the term "self-management" in their resulting literature (Pearce et al., 2015; Parke et al., 2015). Researchers also note that appropriate outcome measures to gage the effectiveness of these interventions are still to be found (Boger et al., 2015). Some of these systematic reviews are further discussed below, followed by commonly used self-management programmes.

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2.5.1 Systematic reviews of self-management strategies in stroke

2.5.1.1 “Self-Management: a systematic review of the outcome measures adopted in self-management interventions for stroke” (Boger et al., 2013).

The aim of this review was to assess the psychometric properties of the outcome measures used in stroke self-management programmes in order to advise all stakeholders about all the aspects of the outcome measurements in use and then make the appropriate recommendations for further development and improvement in the measurement of self-management in stroke.

The study determined that outcome measures for self-management have questionable reliability and validity, and therefore contributes to the inability to correctly gage the effectiveness of a self-management programme in stroke. The authors (Boger et al., 2013) suggested that further research into how the concept of self-management in stroke functions, in order to better clarify the selection of current outcome measures and develop new ones. They encouraged researchers and clinicians to appropriately select outcome measures when implementing a self-management programme, in order to help with the effective evaluation of these programs.

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2.5.1.2 “Experiences of self-management support following a stroke: A Meta-review of qualitative systematic reviews” (Pearce et al., 2015).

The aim of this meta-review was to update the current development and delivery of self-management support interventions, by finding evidence that proves whether supporting self-management in stroke patients realistically has an effect on functional and psychological outcomes, as there currently is a shortage of evidence.

The meta-review showed that stroke survivors experienced the effect on many aspects of their lives post stroke overwhelming. Some of these aspects included emotional and psychological

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support, especially once physical recovery starts to plateau; a real need for further social support; the ever fluctuating need for support across the course of recovery; and the great need for information for the family and patients during recovery. The term "self-management support" was sparsely found, but the core fundamentals of self-management were found.

The researchers concluded that it is important that one has to be cognizant of self-management support needed post stroke during all stages of recovery and that there is a definite need for more qualitative research about self-management support interventions and their implementation.

2.5.1.3 "Self-management support interventions for stroke survivors: A systematic meta review" (Parke et al., 2015)

The aim of this meta-review was to determine whether self-management interventions in stroke patients are effective, as these interventions are often promoted for patients with long-term conditions. The review would then be able to inform healthcare policy makers about provision of the appropriate services.

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The review showed that, although the term "self-management" was not used often, most elements of the concept were found to be part of rehabilitation therapy interventions. They found strong evidence that supported self-management as part of a rehabilitation setting, if delivered soon after the patients experienced a stroke (<1 year).

The researchers concluded the term self-management is rarely used in literature when used in the post stroke context, but aspects of the core concepts of self-management support are made use of in rehabilitation and has enriched therapy outcomes.

2.5.1.4 "Self-efficacy and self-management after stroke: a systematic review." (Jones & Riazi, 2011)

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The researchers' aim for this review was twofold, firstly it was to look at how self-efficacy impacts post-stroke rehabilitation outcomes; and, secondly, to explore the evidence supporting self-management interventions in stroke patients that are based on self- efficacy principles.

They found that there is evidence that self-efficacy is part of various outcomes post stroke, including depression, quality of life and, to a certain level, physical functioning. The review also found that, if based on self- efficacy principles, there can be an advantage when implementing programmes that focus on self- management, but the best format for implementing these interventions is still not clear.

In conclusion, they noted that all stakeholders, including researchers, have to work together in order develop and assess possible interventions that can improve and support self-management skills, so that stroke patients can be more confident and make better progress post stroke. The researchers felt that, by doing this, one can decrease the bad aspects like social isolation, following a stroke.

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2.5.2 Commonly used self-management programmes

Self-management programmes that are often used for chronic conditions include: The Bridges Self-management programme; the My Moves program; the Diabetes Self-Management Education (DSME) Program; and, lastly, the Arthritis Self-Management Programs (ASMP).

2.5.2.1 The Bridges Self-Management Programme

This self-management programme was developed in the UK and adapted in New Zealand. It is based on self-efficacy principles designed to support stroke survivors while they cultivate effective strategies for handling their lives after a stroke (Jones et al., 2009). It was designed in consultation with stroke survivors and their families and makes use of a work book as an instrument to assist

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with recording goals, useful strategies and progress (Bridges SMP, online) and close support from health care professionals (Jones et al., 2009). The self-management booklet consists of 14 "stories" or case studies about stroke survivors, detailing their journey and techniques/coping mechanisms that they found helpful post stroke and discharge home.

A study exploring stroke, carer and HCP's perspectives on the Bridges SMP by Mc Kenna, Martin, Jones, Gracey & Lennon (2015), concluded that the SMP provided support for both health professionals and stroke survivors and both parties agreed that it was beneficial, although further research is still needed regarding content, appropriate timing and the delivery of the SMP.

2.5.2.2 The myMoves Program

The myMoves program is a remotely delivered self-management programme (Jones, Dear, Hush, Titoy & Dean, 2016), initially designed to increase the physical activity of adults with acquired brain injury. Acquired brain injury (ABI) can be defined as damage to the brain that has happened after birth, and is usually caused by a stroke or trauma (O'Rance & Fortune, 2007). The aim of this programme is to offer support to patients with an ABI who are living in the community without having face-to-face contact with the patient. The programme consists of six modules that are delivered by an experienced physiotherapist via the telephone or email, over a period of 8 weeks (Jones et al., 2016).

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All program material is sent via email, in an easy-to-read PDF (portable document format) file. A detailed schedule outlining the myMoves Program is also attached. At the beginning of each week of the program, the participants receive the course materials for that week. In week six and eight respectively, the participants are not provided with new information, in order for participants to strengthen their newly acquired skills. They are encouraged to work through each lesson at their

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own pace for about 30 to 60 minutes. They could however, re-examine the material as often as they wanted to and engage with the course material for 3 to 4 hours over the course of the week, reflecting on and practicing the skills taught in that module. Participants are then contacted either via email or telephonically, at least once per week; the aim of contact is to ensure that the participants' concerns were addressed; skills taught could be adapted to suit the patient and their needs; and to ensure that the patient understood the course work. (Jones et al., 2016). The programme was found to be acceptable and feasible but still requires further research.

The programme has been adapted recently for the use of elderly patients, by Dr T. Jones. The programme is delivered by the same method as the original myMoves program and aims to assist senior citizens (over the age of 65) to become more active; assist with increasing their knowledge and skills; and simply have better health and a sense of wellbeing (sydneynorthhealthnetwork.org.au).

2.5.2.3 Arthritis Self-Management Programs (ASMP)

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The ASMP was created at the Stanford Patient Education Research Centre in the 1970s, specifically for individuals suffering from arthritis (Lorig & Holman, 2003). It is grounded in the self-efficacy theory and is community-based. Barlow, Turner and Wright (1998) found that this community-based intervention showed overwhelming evidence that arthritis sufferers can benefit greatly from the intervention. The American College of Rheumatology Subcommittee on Osteoarthritis Guidelines (2000) recommended that it was of utmost importance that a self-management plan be implemented for patients with arthritis. Lorig, Ritter, Laurent and Plant (2008) developed, evaluated and refined the ASMP for English and Spanish arthritis sufferers.

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The aim of the ASMP is to assist arthritis sufferers to gain control and confidence in their everyday lives, as well as adapt to their condition. The program is run over a six-week period and is made up of a weekly session that lasts for just over two hours, the aim of the workshop is that the participants are interactive. In these group sessions they are encouraged to share their experiences and share suggestions with one another about arthritis-related issues and participate in educational sessions as well. They are taught and encouraged to practice self-management techniques that are tailor-made for them. After each weekly session, the patients are encouraged to practice the recommended self-management techniques at home and report back at the next group session. These group sessions are facilitated by two instructors and can be facilitated by either lay people or health professionals, but it is imperative that at least one of the facilitators has arthritis. These facilitators must attend a four-and-a-half-hour training session before leading these groups. These sessions include, but are not limited to, various topics such as "exercising and using medications appropriately", "making informed treatment decisions" and "problem – solving to address obstacles specific to arthritis" (Centre for Disease Control, 2011).

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Various studies (Buszewics, Rait, Griffin et al., 2006) found that patients who make use of the ASMP show marked improvements in psychosocial outcomes, quality of life and improved disease symptoms; these benefits can last for up to 12 months.

A meta-analysis by Barlow, et al. (2009) examined 24 studies on the ASMP. The results showed that those who used the ASMP had significant improvement in their physical health status (pain, functional disability and fatigue); health behaviors (cognitive symptom management, exercise and better communication with doctors); utilization of health care services (doctor's visits); psychological health (depression, health distress and anxiety); and self-efficacy (general self – efficacy, self-efficacy for pain management and self-efficacy for managing other symptoms).

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When looking at the definition of self-management, this SMP addresses all the aspects of self-management; it involves and encourages the active participation of the arthritis sufferer and their support system (family and /or carer); facilitates education about their chronic illness and how to manage it, but allows them to make decisions about what suits and works best for them, thus facilitating self-efficacy.

2.5.2.4 Diabetes Self-Management Education (DSME) Programs

DSME comprises interventions focusing on a short-term intervention is usually based on a short-term temporary intervention that will or will not include some form of follow up (Funnel, Tang & Anderson, 2007). These interventions aim to equip diabetes sufferers to manage their illness; buy employing strategies such as preventive foot and eye care, insulin therapy, stress and medication management; and education about nutrition (Mensing et al., 2000). DSME programs are widely recommended and are often implemented where there are available resources (Dube et al., 2014 Ezenwaka & Eckel. 2011). The basic standards for a DSME must consist of a program structure, continuous input from professionals, access, adequate programme coordination, trained staff – must include at least 1 registered dietitian, a registered nurse, a pharmacist or certified diabetes educator, – curriculum, an individualized program taking into account the patients' needs, ongoing support, monitoring of patient progress and quality control (Haas et al., 2014).

Like the ASMP discussed earlier, the DMSE is run by two trained facilitators (one of which must have diabetes), the programme is run over a course of six weeks in various locations (at a cost). Topics discussed include (but are not limited to) healthy eating habits, taking medications correctly, managing anxiety, relationship building with health care providers and exercise (Centre for Disease Control, 2011.

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Over the past few years the approach to diabetes education has changed exponentially, with a main shift being a specific focus on patient-centered education and care (Glasgow et al., 2002; Rubin, Anderson & Funnel, 2002; Williams & Zeldman, 2002).

2.6 PERCEPTIONS AND EXPERIENCES OF HCPS AND PATIENTS WITH SELF-MANAGEMENT

Mead and Bower (2000) report that the appeal for patient-centered health care is essential and that the combination of high rates of poor adherence to treatment and the patient's right to choose (UK Department of Health, 2003) points to the importance of exploring and understanding patients' expectations and beliefs (Main, Foster & Buchbinder, 2010). Kidd, Lawrence, Booth and Rowat (2015) found that, in order to successfully execute self-management programmes, health care professionals and stroke survivors must be consulted. Kennedy, Rodgers and Bower (2007) noted that many self-management programmes are unsuccessful because these programs do not focus on patients' needs, preferences and abilities. Similarly, health care professional's reluctance to adjust their well-known more practiced treatment strategies, to be more flexible to accommodate the patients' individuality or see self-management as important, lead to the failure of these interventions (Kennedy et al., 2007; Blakeman et al., 2006; Kennedy et al., 2013). Patients' and HCPs' views relating to self-management, stroke and rehabilitation are further discussed below.

2.6.1 The Perception of Self-management

In a qualitative study by Sadler, Wolfe, Jones and McKevitt (2017), they found that there were marked differences between how self-management is understood by stroke survivors and HCPs; they concluded that language barriers and strategies used by the HCP should be explored further. Furthermore, a Qualitative Metasynthesis by Mudge, Kayes & McPherson (2015), which explored

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clinicians' (HCPs') view of their role in self-management, found that the implementation of self-management in practice was a multifaceted process, and control arose as a main issue in all studies reviewed. They concluded that there should be a shift of control in the patient-HCP relationship.

A meta-review of qualitative systematic reviews of stroke survivors' experiences of self-management support post stroke, found that the provision of self-management support should focus on recognizing that the support needs of stroke survivors change during the recovery process; patient-tailored support through all phases of recovery; social groups for stroke survivors; and a shared relationship between HCPs and stroke survivors – with control, respect and value during recovery (Pearce et al., 2015). In a qualitative study by Jones et al. (2012), suggestions concurred with Pearce et al. (2015), noting that a more shared, collaborative relationship between HCPs and stroke patients needs further exploration in order to provide further support.

A qualitative study by Dube, Rendall-Mkosi, Van den Broucke, Berg & Mafutha (2017), based in a rural South African setting, highlighted that patients and service providers (nursing professionals), have different experiences and perspectives regarding treatment and the self-management of chronic diseases. The study noted that, although patients were willing to be more involved and were open to learning more about their conditions, the HCPs need more training in order to ensure better self-management support for their patients.

2.6.2 Rehabilitation and rehabilitation services

A study conducted in the Western Cape by Kumerenzi et al. (2015), which explored patients' and service providers' (multi-disciplinary) experiences of out-patient rehabilitation services, found that both groups reported similar experiences regarding accessibility, intensity of rehabilitation and patient education. The study highlighted the need to improve services by improving access

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(providing transport) and improving the capacity of the service providers. Ntamo et al. (2013), explored factors affecting attendance for outpatient physiotherapy by stroke patients in Mthatha; the participants (stroke patients) also named transport as a factor for attendance and, essentially, capacity of service providers, as there were not enough therapists to provide an adequate service.

2.6.3 Perception of life post stroke

A study by Ahuja et al. (2013) explored the experiences of patients following a stroke in New Zealand; they found that patients struggle to accept this new part of their lives, but that being in control was more important than goal setting, that a positive attitude was important, that they had to adjust to new limitations and that the involvement and support of the community and family members were important. The study concluded that this promoted self-management and self-efficacy, which would positively impact recovery. They suggested that further studies be done on exploring health professionals' understanding of recovery post stroke.

2.7 SUMMARY OF LITERATURE REVIEW

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In summary, stroke is one of the main causes of long-term disability. The most common management of stroke and its resulting impairments is rehabilitation. However, post in-patient rehabilitation discharge, patients are often referred to outpatient facilities where many factors hinder attendance. Over the years, self-management programmes have been used in the treatment of long-term conditions. Recent research has shown that integrating a self-management programme with a stroke rehabilitation programme has positive outcomes. However, in order to implement these programmes successfully, the input of both stroke survivors and the health care professionals who aid them is essential.

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CHAPTER 3: METHODOLOGY

3.0 INTRODUCTION

In this chapter, the researcher provides a description of the study setting for parts one and two of the study. Part one of the study explores the perceptions of health care professionals regarding self-management using focus group discussions. Part two of the study explores the perception of self-management by stroke survivors using in-depth interviews. The study design, study population, sampling method and instrumentation are described clearly and the procedure of data collection, as well as the data analysis that was conducted is explained. To conclude this section, the ethical considerations relating to the study are stated.

3.1 STUDY SETTING

Both Booth Memorial Hospital (BMH) and Life Ensidimeni Intermediate Care (LEIC) were used as the study settings for part one of the study. Only Booth Memorial Hospital (BMH) was used for part two of the data collection. Both Booth Memorial Hospital in the Cape Town Health District and Life Esidimeni Intermediate Care in the Mitchells Plain Area are nonprofit organizations subsidized by the government. They are step-down facilities aimed at rehabilitation that admit acute and sub-acute patients referred from tertiary and secondary hospitals. A step-down facility refers to a facility that provides low intensity rehabilitation (Western Cape Government, Rehabilitation Services, retrieved from www.westerncape.gov.za, 2018). BMH has 106 beds and LEIC has 220 beds. Both receive referrals, mainly from the Western Cape and also from surrounding areas.

Life Esidimeni Intermediate Care and Booth Memorial Hospital admit patients with various conditions such as orthopedic, surgical, medical, palliative and immuno compromised patients.

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The stroke patients that are admitted to both facilities range from mild to severe levels of impairment.

Each facility has a team of HCPs that screen applications; admission criteria include severity of wounds, level of consciousness, rehabilitation potential, discharge plans and reason for admission (convalescence, rehabilitation, respite or palliation), to name a few. During the patients' admission they gain a holistic rehabilitation treatment approach, involving speech therapy, occupational therapy, physiotherapy and, if needed, nutritional support. Regular multidisciplinary team ward rounds and meetings are held, and family meetings and training sessions are arranged.

Once a stroke patient is admitted into the ward at BMH, he/she is first assessed by the medical officer and then referred for rehabilitative therapy by the occupational therapist, physiotherapist and speech and language therapist. Therapy sessions are individualized; however, if there are patients with similar levels of disability, groups are handled in physiotherapy. The occupational therapy service also runs group sessions for motivation and support. As patients progress and become more independent in their ADLs, the nursing staff plays a large role in the everyday integration and application of activities. They also assist with mobilization (transfers, bed mobility and walking), once deemed appropriate by the therapy team. The social worker is involved from admission to discharge and assists the families.

Once the stroke patients at LEIC are admitted to the facility, an initial assessment is performed by the nursing staff, followed by the medical officer, who would then refer the patient to the multidisciplinary team (MDT) for physiotherapy, occupational therapy, speech, dietetics and social work depending on the needs of the patient. Following their assessment, the patients start with their rehabilitation programme, which could include individual or group therapy interventions. The groups are run on the basis of the psycho-social rehabilitation model to ensure

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that the patient is attended to holistically, rather than only physically. The MDT would meet weekly to discuss the patients' assessment, progress and plan; and ensure that the patient-centered goals were MDT-aligned and integrated.

Upon discharge from LEIC and BMH, all patients are referred to home-based care services and patients who require further therapy and have potential to further improve are referred to community-based out-patient facilities or private therapy.

3.2 STUDY DESIGN

A descriptive, exploratory design within a qualitative research approach was used for both parts of the study. The descriptive exploratory design can be defined as the primary research for a new or a poorly understood idea, thus laying the foundation or groundwork for future research (Neergaard, Olesen, Anderson & Sondegaard, 2009). This approach provided a comprehensive summarization of experiences that deal with the "why", "how" and "what" questions regarding the perceptions of health care professionals and patients of self-management programmes. The qualitative approach promotes a more natural style of observing a particular phenomenon (Sandelowski, 2010) and is grounded in people's everyday realities, pursuing the need to understand how people experience and cope following a catastrophic event such as a stroke (Hammell, Carpenter & Dyck, 2000). The qualitative research approach was used rather than a quantitative approach, as the study aimed to explore patients' and health care professionals' everyday realities, experiences and understanding of self-management, thus getting a richer data set, whereas a quantitative approach uses more objective and mathematical methods.

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3.3 PART ONE – FOCUS GROUP DISCUSSIONS

3.3.1 Study population and sampling

3.3.1.1 Study Population

The study population (30) consisted of the health care professionals of both Life Esidimeni Intermediate Care (16) and Booth Memorial Hospital (14) for part one of the study. The population of the health care professionals consisted of registered nurses, physiotherapists, speech therapists, occupational therapists, social workers and doctors working in the step-down facilities and involved in the rehabilitation process.

3.3.1.2 Study Sample

The study sample consisted of the health care professionals who agreed to participate and who were available on the day of the focus group discussion (FDG). The FGD at BMH consisted of five participants and there were 13 participants in the LEIC FGD. A convenient sampling method was therefore used with the health care professionals. Convenient sampling can be defined as a technique by which participants are selected according to their accessibility, proximity and availability (Handcock & Gile, 2011). This method was used as it is useful for collecting usable data and information and therefore is fast and efficient. However, some disadvantages of convenient sampling include bias, which can lead to under representation or over representation of the population and therefore affect the ability to generalize, which may affect the study (Saunders, Lewis & Thornhill, 2012).

The HCPs were available at the time of the FGDs and were in close proximity as FGDs were held at their places of employment; the area where the FGDs were held was also easily accessible. The HCPs also were the sources of information that was required for the study.

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Data saturation was achieved when no new themes and sub themes emerged (Hancock, Amankwaa, Revell & Mueller, 2016).

3.3.1.3 Inclusion and exclusion criteria

The participants in the focus group discussions were all HCPs who formed part of the rehabilitation of stroke patients at the time of data collection.

3.3.2 Study Instrument Used

3.3.2.1 Interview Guide

An interview guide based on relevant literature (Hale et al., 2014) was used for both the focus group discussions and the in-depth interviews. An interview guide assists the researcher to guide the interview and collect in-depth information from participants (Knight, 2013). It enables the researcher to have some control over the interview, i.e. time, questions asked (Gill et al., 2008), the literature explored, self-management and stroke survivors.

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One interview guide was used for both phases of the study. The questions were formulated using previous studies by Hale et al. (2014). Questions included: What do HCPs think self-management is? and Do they feel a self-management programme can be used as part of a rehabilitation programme in a South African setting?"

3.3.3 Data Collection

3.3.3.1 Data Collection Methods

Two focus group discussions with HCPs were conducted, after obtaining permission to conduct the study as described in the section on ethical considerations. Focus group discussions are used to obtain data quickly from several people (Mouton & Babbie, 2015). The benefit of using FGDs

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include that they are helpful when exploring individuals' experiences and understanding of a topic, while exploring how they think and reason; it also allows for the discussion of key concepts, as one individual follows onto what someone else has said (Mouton & Babbie, 2015). The focus group discussions gave the HCPs a chance to express opposing views and ideas, therefore adding fullness to the dataset (McLafferty, 2004). One focus group was held at each of the facilities and was facilitated by two researchers, both involved in stroke rehabilitation.

3.3.3.2 Data Collection Procedure

All participants where employed at the two facilities used in the study; each participant was contacted individually either via phone call or in person by the researchers and a convenient time was arranged for all members of the group. The focus group met in a pre-selected room to ensure privacy, confidentiality and avoid any distractions.

The focus groups were voice recorded by each of the researchers, to ensure accurate recording of the session. Each researcher presented their own set of predetermined questions. The focus groups were conducted in English and ran for 30 to 45minutes. The background and aim of both studies were explained to the participants and consent was obtained, participants also signed a focus group confidentiality binding form.

The participants from both focus groups attended a workshop on self-management presented by one of the researchers. However, the Booth Memorial focus group had the self-management workshop on the same day as their FGD, while the LEIC group had had the workshop several weeks before the FGD. The workshop consisted of a presentation of the definition of self-management and the Bridges self-management program – exploring self-efficacy and practical uses of self-management. The session was interactive and required the participants to interact with

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each other and the researchers; it aimed to familiarize participants with the concepts of self-management. They were then issued with the Bridges Self-management Programme and given 30 minutes to familiarize themselves with aforementioned reading material. The Bridges self-management Programme was then used as a reference for the FGD.

Each focus group was facilitated by both researchers and by using questions included in their respective interview guides.

3.4 PART TWO – IN-DEPTH INTERVIEWS

3.4.1 Study Population and Sampling

3.4.1.1 Study Population

Stroke patients admitted to Booth Memorial Hospital at the time of the study comprised the population for part two of the study. The population of stroke patients during the period of the interviews comprised 35 males and females.

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3.4.1.2 Study Sample

The stroke patients were selected via purposive sampling. This sampling method was used as the participants were selected for a specific reason (Carter & Little, 2008). This type of sampling is based on the discretion of the researcher and represents typical characteristics of the population (De Vos, 2002). The stroke patients were thus chosen according to particular characteristics, which included the patient's gender and severity of stroke. The severity of stroke was classified as mild, being a survivor of a cerebral vascular accident (CVA) leading to minor disability that does not limit ADLs; moderate, being a survivor with permanent or residual hemiparesis following CVA – patient is still capable of some basic independent functioning, needs assistance with some ADLs;

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and severe, where the survivor is left with permanent disability caused by a CVA, expecting no physical recovery and presenting with global aphasia and therefore needing maximal assistance. The inclusion criteria entailed that the patient had to be an in-patient at BMH, older than 18 years and able to interact verbally with the interviewer. A total of 11 participants were recruited for the study. This was sufficient to address the aspect of saturation which is reached when information regarding a topic becomes repetitive and no new information is gained, which is usually between 6 to 10 interviews (Guest, Bruce & Johnson, 2006). Saturation was also considered when recruiting participants.

3.4.1.3 Inclusion and exclusion criteria

Patients were included if they had a definite diagnosis of stroke. This was determined by the CTB results recorded in their referring hospital's referral letter, and patients were excluded if they had a speech or cognitive impairment. This is further explained in the procedure.

Table 3.1: Classification

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Classification	Description
Mild	Cerebral vascular accident (CVA) leading to minor disability that does not limit ADLs.
Moderate	Permanent or residual hemiparesis following CVA, patient is still capable of some basic independent functioning, needs assistance with some ADLS. May have aphasia.
Severe	Permanent disability caused by CVA, no physical recovery, presents with global aphasia and severe visual impairment. Needs maximal assistance.

3.4.2 Study Instrument Used

The Same instrument as mentioned in 3.3.2 was used, due to the fact that the objectives of the study were the same for both parts of the study.

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3.4.3 Data Collection

3.4.3.1 Data Collection Methods

Eleven in-depth interviews were conducted, after obtaining permission to conduct the study, as described in the section concerning ethical considerations. An in-depth interview explores an individual's perspective on a particular subject or topic (Milena, Dainora & Alin, 2008). A research assistant who has a Master's degree in industrial psychology and experience with facilitating research interviews was recruited to assist the researcher with data collection. The researcher was unable to conduct the interviews herself, as she is employed by BMH, thereby avoiding data collection bias, by which the researcher's personal beliefs could influence the way the data are collected (Smith & Noble, 2014). After the recruitment, the following data extraction strategies were used in order to avoid bias: All participants were selected from the hospital patient list, which was made available by the head of therapy at BMH according to criteria mentioned in section. These participants were then purposively selected by the Head of Therapy at Booth Memorial Hospital, as the researcher is employed at the aforementioned facility.

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3.4.3.2 Procedure

The head of therapy selected participants who met the inclusion criteria: the participant had been diagnosed with a stroke as per their hospital file. Speech and cognitive impairments were excluded, according to occupational therapy input, and this was determined by the general assessment completed by the occupational therapist. The head of therapy is an occupational therapist who works closely with the patients and was therefore familiar with their level of cognitive impairment and speech impairments.

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The in-depth interviews were conducted at Booth Memorial Hospital, in a room identified as private, confidential and void of any distraction. The patients that were identified were approached and given information sheets and the aim of the study was explained to the patient by the head of therapy. All participants were able to give written consent. A convenient time for both the patients and research assistant was agreed upon. The interviews were held over a period of three weeks and were conducted in the preferred language of the participants.

Once in the interview room the research assistant explained the study and purpose of the study to participants and consent was again obtained. All discussions with participants were done in their home languages. The participants were then asked a series of questions regarding self – management. The interviews were guided, based on literature and the researchers' experience. Interviews lasted between 15 minutes to half an hour. All interviews were tape-recorded and field notes were taken.

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3.5 QUALITATIVE DATA ANALYSIS OF PART ONE AND TWO OF THE STUDY

The six steps/phases for thematic analysis were followed as stated in Braun and Clark (2006). All tape-recorded interviews were transcribed in full by an independent party. All the transcriptions were read numerous times and compared with the audio recordings to confirm accuracy (Neumann, 2000). All transcriptions were in English and the researcher read and re-read the transcriptions several times to become familiar with the material. The researcher then analyzed those transcriptions and interesting features in the data were coded in a systematic way, across the data set, collecting data relevant to each code. The codes were then collated into potential themes, gathering all data that would fit into each potential theme. The themes were checked to gage

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whether they worked in relation to the coded extracts and the entire data set. The analysis was on-going in order to perfect the specifics of each theme, thus generating clear definitions and names for each theme (Miles & Huberman, 1984; Spencer& Ritchie, 1994). The participants were coded to protect their anonymity.

3.6 TRUSTWORTHINESS OF THE QUALITATIVE DATA

Three of the four aspects of trustworthiness were applied to this study for quality of the data (Lincoln & Guba, 1985): credibility, dependability and confirmability. In order to improve the three criteria, various strategies were employed. For credibility, participants of the focus group discussions and in-depth interviews had the opportunity to check the summarized transcripts in a language they understood, to ensure that the information was transcribed correctly. The health care professionals were provided with summarized transcripts for member checking. The independent researcher shared a quick summary with the participant at the end of the interview. For dependability, a code and recode procedure was used to ensure this. Regarding confirmability, the data were discussed with peers and experienced colleagues, for peer examination. The transcriptions were also reviewed by the study supervisor.

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3.7 ETHICAL CONSIDERATIONS

Permission to conduct this study was obtained from the Humanities and social sciences research ethics committee at the University of the Western Cape, Booth Memorial Hospital and Life Ensidimeni Intermediate Care.

Participants in the focus group discussion were given an introduction regarding the study and were given information sheets and then signed written informed consent, as well as a group confidentiality form to ensure anonymity.

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The in-depth interview

Participants were given an information sheet in the language of their choice. When they felt uncertain, they were encouraged to discuss participation with their family members. Information sheets were read out loud for participants who were visually impaired. Signed written informed consent was obtained from participants.

All participants were assured of respect, confidentiality and anonymity. All participants were interviewed in an appropriate room in order to maintain confidentiality; their names were not used during the interviews and were not made known to the other participants to protect anonymity and were respected throughout the interview process. All participants in the focus group discussions and interviews agreed to being audiotaped. All transcribed data and audio tapes were kept in locked filing cabinets. Electronic information was stored using password-protected computer files. All participants took part in the study voluntarily, and they had been informed that they were free to withdraw from the study at any time. Participants were told that counseling services would be made available, should anything happen to upset them during the focus group discussions or interviews. During the study, no participant needed counseling. The research assistant signed a confidentiality agreement form.

The final version of the study results will be made available to the staff of the Booth Memorial Hospital and Life Esidimeni Intermediate Care.

3.7 SUMMARY OF THE CHAPTER

In this chapter, the study setting comprising Booth Memorial Hospital and Life Ensidimeni Intermediate Care was described. The researcher has discussed the methods employed in the study. A qualitative approach using in-depth interviews to explore stroke patients' perception of self-

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management and focus group discussions held at each facility to explore health care professionals' perception and understanding of self-management was utilized. Once the collection of qualitative data had been completed, thematic analysis was undertaken. The discussion of sampling methods used and the ethical considerations pertaining to the current study are also included in this chapter.

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CHAPTER 4: QUALITATIVE RESULTS OF PART ONE AND PART TWO OF THE STUDY

4.0 INTRODUCTION

The results of part 1 and part 2 of the study are presented in this chapter.

In part 1, the focus group discussions were used to explore the health care professionals' understanding of the concept of self-management, the perceptions of the application of self-management strategies by stroke survivors and the integration of self-management strategies into current rehabilitation programs. This chapter begins by describing the focus group discussions, which explored the views of HCPs on the definition of self-management and its application in the local setting and then continues to present and discuss the categories and themes that arose. While presenting the findings, verbatim quotations from the FGD are used in order to illustrate the themes.

Part 2 of the study utilized in-depth interviews to explore the stroke survivors' understanding of the concept of self-management, the perceptions of the application of self-management strategies and the integration of self-management strategies into current rehabilitation programmes. This part of the chapter begins with a description of the participants and then the categories and themes which arose from the in-depth interviews are presented and discussed. Quotations from the categories and themes are presented verbatim in order to illustrate interviewees' responses.

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Two FGDs were conducted, one at each of the health care facilities which were part of the research setting. The number of participants per group were 5 and 13, with the BMH group having 5 participants and the LEIC group having 13. The groups ran for 30 to 45 minutes and were facilitated by the researcher. The groups comprised physiotherapists, occupational therapists, speech therapists, social workers and registered nurses. As mentioned previously in the section dealing with the methodology, all participants were labeled according to their professions to maintain anonymity. From here on out The Bridges self-management Programme which was shared with the participants was used as a reference for a stroke self-management programme. Table 4.1 presents a description of participants for both focus groups. The groups have been combined in order to maintain anonymity, as there was only one occupational therapist in one FGD.

4.1 PART 1 OF THE STUDY - THE QUALITATIVE RESULTS OF THE FOCUS GROUP DISCUSSIONS

4.1.1 Description of Focus Group

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Table 4.1; Focus group participants

Participant	Profession
1.	Physiotherapist
2.	Physiotherapist
3.	Occupational Therapist
4.	Occupational Therapist
5.	Social Worker
6.	Speech and Language Therapist
7.	Dietician
8.	Registered Nurse
9.	Physiotherapist
10.	Occupational Therapist
11.	Social Worker
12.	Registered Nurse
13.	Registered Nurse
14.	Physiotherapist

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15.	Speech Therapist
16.	Occupational Therapist
17.	Registered Nurse
18.	Registered Nurse

4.1.2 FGD Results

4.1.2.1 Participants' understanding of self-management

Table 4.2: Themes, categories and codes for Participants' understanding of self-management - FGD

Themes	Categories	Codes
Taking responsibility for the management of their condition	Knowledge about condition	• Understanding
	Responsibility for their rehabilitation	• Responsibility • Cope
Not dependent on others	Manage own impairments	• Reliant
	Managing their circumstances	• Manage • Problem
Regaining the ability to conduct activities	Relearn ADLs	• Activities
	Attempting and finishing tasks	• Try • Attempt

Three themes emerged in response to exploring the participants' understanding of the concept of self-management. These included taking responsibility for the management of their condition, dependence on others, and regaining the ability to conduct activities.

4.1.2.1.1 *Taking responsibility for the management of their condition*

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The participants expressed that self-management involves that patients with long-term conditions such as due to a stroke would take responsibility for the disabilities that result as a consequence of the stroke as is expressed in the quotations below.

"I would have thought that it would be, to be able to cope with whatever disability you've got, but then very quickly I like the fact that they've got a voice a choice [because of self - management]."

Furthermore, they indicated that the individuals should also take responsibility for being knowledgeable about their condition.

"Understanding your condition, where you are now, what you can't do, but you know you would like to get it."

With regard to taking responsibility, they also expressed the need to take responsibility for the rehabilitation which includes setting goals for both the rehabilitation and the recovery process.

"Taking responsibility for their own actions, having to set goals for themselves and having to understand what it is that they need to do in order to reach these goals."

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4.1.2.1.2 Not *dependent on others*

The participants also felt that self-management involved stroke survivors not depending on others in order to manage impairments associated with a stroke.

"And also to like not being reliant upon somebody else…and do some things for yourself and be responsible for yourself."

"So obviously not doing everything, but trying at least to assist rather than getting someone else to do it for them. So try as much as possible and then if you need assistance…"

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Expanding on not being dependent on others, the participants highlighted that self-management include being able to manage yourself after being discharged. The participants also expressed that self-management involved managing their circumstances.

"Manage themselves after discharge from hospital"

"How they are able to manage their lives without the help of somebody else"

4.1.2.1.3 *Regaining the ability to conduct activities*

The third theme that emerged was the patients' ability to regain function once they return home, especially with regards to ADLs.

"Are able to eat by themselves, or wash themselves"

"Getting back to their activities of daily living and how they function in their own environment"

Additionally, taking part in or attempting to finish tasks set out:

"Participate in completing everything else themselves, so doing as much as possible"

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4.1.2.2 Participants' views on whether a self-management program will work in a local (South African) setting/context

Table 4.3: Themes, categories and codes for Participants' views on whether a self-management program could work in a local (South African) setting/context - FGD

Themes	Categories	Codes
Government Resources for rehabilitation	Inadequate resources	• Time • Alleviate pressures • Staffing
	Correct implementation	• Training
Motivates and promotes self-confidence	Monitoring/ recording progress	• Motivation/al

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South Africa's diverse culture and socio economic background	Level of literacy	• Access • Literate • Educational level
	Cultural differences and sensitivities	• Behind • Differences • Culture
Dependence on health care professionals	Reliance on medical staff	• Fix • Answers

Four main themes emerged, some highlighting the barriers to the implementation of a SMP as; insufficient government resources, self-management can promote self-confidence and motivation, patients still dependent on health professionals for rehabilitation and South Africa's socioeconomic and cultural background.

4.1.2.2.1 *Government Resources for Rehabilitation*

The health care professionals who felt that a stroke SMP would work in a local context felt that a SMP can alleviate various pressures that are due to poor government resources.

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"Self-management would be a very beneficial, because there is such a limited amount of human resources across the country, in both private and government."

In order to achieve this, they believe that the correct implementation of a SMP is vital.

"It needs to be implemented correctly in the right format, in the right structures, with the proper trained professionals."

However, other participants indicated that, due to poor resources (human and physical), a SMP would add to the burden.

"In order to initiate this tool, would require more than one session... it's not as simple as just handing somebody a book… this can impact on actual therapy sessions and therapy time and resources,"

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Some even felt that some patients would not even get the opportunity to be introduced to a SMP, because they either were not referred for follow up or do not go to their local Community Health Centre for continued therapy.

"... there is a lot of patients who have strokes and [often] they are sent home without any physio, ...then they come to us a few months later, and it's a bit too late by then, unfortunately, so I think if you could implement [self-management] at an earlier stage [prior to discharge]"

4.1.2.2.2 *Motivates and promotes self-confidence*

Participants felt that a SMP can help to foster positive and motivating characteristics in patients, by monitoring/recording progress.

"It [Self-management] will be good, because we can also monitor progress."

"I feel like it[self-management] will work even if it's just from a motivational side."

"... [Self- management] just gives them a motivation to try and push the boundaries."

4.1.2.2.3 *South Africa's diverse culture and socio economic background*

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Participants expressed that the level of literacy of the stroke survivors would affect the implementation of SM in the local setting.

"I would like to see very literate people, with a higher educational level and have access to such a tool."

"Literacy is an issue…they won't be able to cope."

"I think we need to start [self-management], but I think we are possibly a little bit behind in comparison with the rest of the world."

They felt that one should take into consideration the many cultural differences and sensitivities.

"I think also it's quite a wasted idea, [where] self-management, it will work in a first world country where independence is highly valued, it might be more applicable, but not in a rural area."

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"The cultural side of things could be a barrier in the implementation of a tool like this, it is important to understand that we have a lot of different cultures."

Participants alluded to the fact that females may be more motivated to engage in self-management than males.

"It depends on the client; women are usually integral to the running of a household, they do the cleaning and cooking, rearing of the children and would therefore be more motivated, whereas men would be less motivated as there would be children or sisters to assist with or even perform the task for them."

4.1.2.2.4 *Dependence on health care professionals*

Lastly participants felt that patients are still very reliant on health professionals for their wellbeing and healing and implementing a SMP will require a major mind shift for both patients and HCP.

"In South Africa patients prefer doctors/medical professional to give them answers, and therefore we will all need a mind shift"

"We are driving our clients (perceptions) that we are the professionals, and if they come and see me, I will fix their (physical) problems"

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4.2 PART 2 OF THE STUDY - THE QUALITATIVE RESULTS OF THE IN-DEPTH INTERVIEWS

4.2.1 Description of the Participants

Eleven in-depth interviews were conducted with the participants by an independent researcher. (Table 4.4). The characteristics that were used in the purposive selection of the participants, namely age, admission to Booth (being an in-patient at the time of the interview), being older than 18, gender (either gender), and the severity of stroke (being able to interact, therefore cognitive function). Patient conditions were classified as mild, moderate or severe as shown in Table 4.4

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for the purpose of the study. Participants came from various areas, socio economic backgrounds and educational levels. In order to maintain confidentiality and anonymity the transcribed quotations from the interviews will be tabulated in the cryptogram P1 to P10.

Table 4.4: Distribution of the interview participants

Participant	Age	Gender	Severity of Stroke
1.	82	Male	Moderate
2.	77	Female	Moderate
3.	72	Female	Moderate
4.	65	Male	Moderate
5.	64	Female	Moderate
6.	58	Female	Moderate
7.	57	Male	Mild
8.	57	Male	Moderate
9.	56	Male	Mild
10.	56	Male	Mild
11.	56	Female	Moderate

4.2.2 In-depth Interview Results

4.2.2.1 Participants' understanding of self-management

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Table 4.5: Themes, Categories and Codes for Participants' understanding of self-management – in-depth interviews

Themes	Categories	Codes
Being Independent	Doing things for themselves	• Activities • independence
Accepting Assistance from Others	Accept assistance from others	• Do as you are instructed/advised
	Not being an inconvenience	• Burden • Problem
Psychological factors	Changing their mindset	• Faith • Determination • Attitude

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	Dealing with their condition	• Coping • Acceptance • Understanding • Adapting

When exploring the patients' understanding of self-management, three main themes emerged. These themes were being independent, accepting assistance from others and psychological factors.

4.2.2.1.1 *Being Independent*

Participants understanding of self-management focused mainly on what they could do for themselves.

"To get up independently and do things for yourself, that's what I think." V014

"Self-management is myself and what I can do with myself." VN1

They mentioned types of activities they should try and achieve.

"It's better to do things by yourself…. for example, you wash, or try to wash yourself, get dressed by yourself, get yourself up and turn yourself, things liked that." V020

Even though they felt that self-management meant being independent, assistance from others also played a huge role.

4.2.2.1.2 *Accepting assistance from others*

Some participants felt that self-management meant accepting help from those around you.

"You get the person in charge, they give you goals, they give you something to do but you must do so accordingly, what they say you must do…" R2

"To get back into society as quickly as possible, but also not to rush and do what the doctors and physio prescribe. I found it very helpful and that gave me determination." V018

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"If I give my co-operation to the person assisting me, then it will be easier for that person."

VR008

The participants also felt that self-management meant less help from others, not being an inconvenience or a burden.

"It's better to do things for yourself than to be dependent on other people." V020

"You've got to learn to help yourself, as a patient, you cannot expect someone else to do everything for you." VN2

"Even turning in bed or making yourself comfortable to sleep is a major obstacle and you need somebody to come and assist you… …the least you want to do is become a burden to other people" R4

"I don't want to depend on a nurse to do things for me." V014

Being able to cope and manage their current condition and status as a stroke patient also formed a part of self-management.

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4.2.2.1.3 *Psychological factors*

The patients mentioned that self-management meant dealing with the various psychological issues such as acceptance of their current circumstances and coping with the resulting impairments.

Patients felt that self-management included dealing with their condition.

"What I do with my own health, that I come to terms with it and manage my life" VR 005

Participant VN2 expressed that they struggled to come to terms with their stroke, even though she thought self-management was learning to help oneself.

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"Em, it's difficult for me to accept, because I have always been a busy person, I've been active up until the day I got the stroke, so for me it was very difficult to accept, but I'm trying to get used to the idea." VN2

That self – management meant changing their mindset.

"You've got to have faith in yourself, you've got to have determination." V016

"The nurse downstairs said to me, that she was just going to put me in the shower, I said she can't because I'm paralyzed from the waist down, she told me it was all in my mind. That helped me to change my attitude, I washed myself." VN1

"It's already going better because I desire it. To do more for myself, even if its not independently, even if it it's just putting one foot forward. That's at least the beginning, instead of being dependent." VR008

4.2.2.2 Participants' views on whether a self-management program will work in a local (South African) context

Table 4.6: Themes, Categories and Codes for Participants' views on whether a self-management program will work in a local (South African) Context – in-depth interviews

Themes	Categories	Codes
Providing guidelines to recovery.	Knowing more	• Advise • Manage • Warning
	Able to do more	• Able • Help
Aiding in adapting to life post stroke.	Assistance and aids	• Family • Therapist
	Reintegration	• Cope • Adapt • Home • Hospital
Assist in taking ownership of their condition.	Motivation	• Trust • Belief
	Taking responsibility	• Acceptance • Patience

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		• Control

The participants felt that incorporating a self-management program into a rehabilitation program can work in a local context. They discussed the reasons why they felt this way. The following themes emerged and are presented below: providing guidelines to recovery; aiding in adapting to life post stroke; and taking ownership of their condition.

4.2.2.2.1 *Providing guidelines to recovery*

Participants felt that a self-management program would help stroke survivors to know more and educate stroke survivors about their condition.

"If I receive the guidelines that can advise me, I will use something like that. Then I will know what works and what doesn't work" VR008

"If somebody would tell me what I must do because there is a warning if you do this then this (a stroke) will happen and you can train to help yourself." R2

They felt that with a self-management program they would be able to do more.

"We would be able to do more for ourselves if we were taught how to do things, em differently…" VN2

"*We can also try to help ourselves, but we don't know enough in order to help ourselves."* V014

4.2.2.2.2 *Aiding in adapting to life post stroke*

The second theme explored patients' feelings that a self-management program would assist in adapting to life post stroke.

Participants felt that a self-management program could really assist with adapting and reintegrating post stroke.

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"I think it's essential, yes. If I had known much of the things that I am confronted with I would be able to cope better with it but because it's new to me I have to learn and adapt." R4

Participant V016 felt the same as participant R4 and added that a self-management program would assist with the transition from hospital to home life:

"I feel that given the correct instructions and you follow them out, it can work because when I am finished with my therapist in the day time, she tells me how to practice…and when I come down the next morning, I've got to show her what I've done. Providing the people at home has got family or someone that can help them to egg them on and I feel like it can work."

4.2.2.2.3 *Assist in taking ownership of their condition*

The last theme illustrates that patients felt that a self-management program would help them to take responsibility for their own health and recovery, as well as being a motivating factor.

They mentioned that accepting help from others and then implementing what they had learned would be valuable:

"If we patients accept the help and therapy we get and we implement it in our own time then surely the program will go better and quicker and also more people will be able to benefit from it" V018

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Participant VR005, however, felt that, with a self-management program, he would need to depend less on others, as depending on others would indicate poor self-belief –

"If I want other people to assist me, then I will rely on other people, then I have no trust or belief in myself."

Taking responsibility and being accountable was also mentioned with regard to why a self-management program would work in a local context.

"I think self-management will work because it's my body and it means a lot to me…you are putting it (self –management) in my hands and that's great." VN1

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"…much of my rehabilitation is dependent on my effort that I put into it." R4

"In a rehabilitation of any victim of any kind, the hands on ability to help you and show you the way, to show you how it is done in an easier way for yourself. I think that it would be a good thing, but I also think it's going to take a lot of patience and some control." V023

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CHAPTER 5: DISCUSSION OF THE RESULTS OF FGD AND THE IN-DEPTH INTERVIEWS

5.0 INTRODUCTION

The aim of this study was to explore the perceptions of health care professionals and stroke patients in the Western Cape with regard to self-management. This chapter provides a discussion of the findings of the study. The findings from the HCP focus group discussions and the stroke patients' in-depth interviews are discussed around the common aspects, while addressing the objectives of the study. which were to explore the HCPs' and stroke patients' understanding of the concept of self-management; to explore the HCP perceptions of the application of self-management strategies by stroke survivors; and to explore HCPs' and stroke patients' perceptions regarding the integration of a self-management strategies into current rehabilitation programmes.

5.1 THE PARTICIPANTS' PERCEPTIONS OF SELF-MANAGEMENT

This section addresses two of the objectives of the study, the HCPs' and stroke patients' understanding of the concept of self-management and the HCPs' perceptions of the application of self-management strategies by stroke survivors. The findings from both the in-depth patient interviews and the HCP focus group discussions showed that their understanding of self-management revolved around independence, taking responsibility of the condition and regaining the ability to conduct activities. The health care providers focused more on the patients' taking responsibility and being independent, however, whereas the stroke patients still felt that accepting help from others from time to time and considering all psychological factors are important.

When one reviews the results in the light of the definition of self-management, which is the active management by individuals and his/her family of their treatment, symptoms, lifestyle, physical

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and psychological consequences inherent with living with a chronic condition (Effing, 2007; Jovicic, 2006) it is clear that their understanding is focused on all the spheres of self-management mentioned above.

5.1.1 Independence

5.1.1.1 Taking Responsibility of their condition

The HCPs perception of self-management was that it was the ability of patients to take more responsibility for the disabilities resulting from the stroke and to take an active step in acquiring the necessary information regarding rehabilitation, including setting goals. They felt that taking responsibility for their condition will facilitate independence.

Studies show that, even though patients want to take ownership of their condition, they still depend on HCPs to assist with goal setting and execution as they view the HCPs as the experts (Pearce et al, 2015; Mudge et al., 2015; Sadler et al., 2017).

Even though the HCPs feel that taking responsibility is important, research shows that patients struggle post discharge with integration back into the home environment, loss of constant feedback from HCPs and social re-integration (Turner, Flemming, Ownsworth & Cornwall, 2008). This shows that the transition period from an institution to a home setting is a difficult one and emphasis needs to be put on this in order to help facilitate a smoother process for patients assuming responsibility. This indicates that the SMP can be integrally important in patients taking responsibility for their condition post stroke and therefore should assist in the transition from hospital to home.

5.1.1.2 Regaining the ability to conduct activities and Being Independent

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The patients felt that self-management as the ability to regain function once in their home environment was the final theme that emerged from the HCPs, especially regarding their ADLs and taking part in and completing specific tasks. The stroke survivors felt that self-management meant being able to do things for themselves, focusing on basic ADLs.

Both the HCPs and patients felt that the patients' ability to regain function once back in their home environment, especially regarding their ADLs, and taking part in and completing specific tasks was important, with the patients specifically focusing on basic ADLs. The above findings are similar to what was found by Sadler, Wolfe, Jones and McKevitt (2016), who found that HCPs and stroke survivors viewed self-management as the ability to resume everyday activities and participating in "social roles".

Activities that the patients found important were basic ADLs such as bathing, dressing and toileting; as well as taking medication and transferring independently. It is therefore important to consider patients' goals, thereby focusing on a more patient-centered approach, and really taking into consideration the basic ADLs while encouraging more independence.

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The approach that is applied by the HCP when adopting self-management support as part of rehabilitation could facilitate the patients' taking control of their recovery, therefore actively managing their condition, which is one of the main components of self-management. Kennedy et al. (2007) further confirmed this by noting that continued assistance and support from professional and nonprofessional staff is key for successful self-management.

The patients feel that self-management is the ability to be independent, especially when it comes to ADLs, specifically the more intimate activities such as bathing and dressing. One then needs to consider what the goals of the rehabilitation process should be. Therapists tend to focus on

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mobility, regaining general function and general ADLs without taking into account the patients' actual needs, which are usually only addressed prior to discharge. Even then specific techniques are encouraged and what is easier or simpler for the patients is not acknowledged, therefore taking away a more client-centered approach and reducing their independence.

5.1.1.3 Not having to depend on others and Accepting help from others

These two themes seem to contradict each other; the HCPs felt that self-management would promote independence, while the stroke survivors still felt that accepting help when appropriate is important.

HCPs felt that self-management entails the stroke survivors' ability to become less dependent on others, in order to successfully manage their impairments. Highlighting post-discharge self-management specifically, they expected this to facilitate independence. This was the only theme specifically highlighting post discharge self-management.

However, a study by Satink, Cup, De Swart & Nijhuis-van Sanden (2015) that focused on patients' perceptions of self-management post discharge when at home found that patients struggle to adapt once they have returned home. They therefore are not able to immediately take responsibility for their condition. This was similar to findings by Boger et al. (2015), who found that patients felt ill prepared to manage their condition post discharge. These findings differ from the current research results as the patients in this study were still receiving in-patient therapy and had not yet experienced their home environments post stroke, whereas the participants reported in the literature had already been exposed to their home environments.

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Satink et al. (2015) also found that not having professional support post discharge was very difficult for stroke patients; their study noted that stroke patients would have appreciated extra emotional and psychological input and support.

The themes also highlight the patient and HCPs views that self-management means independence; patients do not want to be dependent on others for assistance once discharged home.

While patients felt that self-management meant accepting help from others, this moves away from the theme of independence. They felt that, for self-management to be successful at home, they would have to accept some help from caregivers, family members and health professionals in order to reintegrate back into their home environments.

Satink et al. (2015) found that while patients were trying to self-manage at home, they were still being co-managed by family members. This led to continued support by family members but also restricted the development of their ability to self-manage. This is similar to what the stroke patients in this study felt about self-management, namely that, even though independence was important for stroke survivors, it was important that they accepted help, as it was important for recovery/rehabilitation. It was also noted that, even though they should accept help, they should be cautious not to become a burden to those who offer the help. It could be that there needs to be a transition period, during which some assistance is needed in the period immediately post discharge which could decrease as the patient becomes more independent in the home environment. Self-management techniques or practices could be employed during this period, by providing education and support to bridge the gap in this transition period, as patients can still successfully apply self-management principles with or without assistance from others.

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5.1.2 Psychological Factors

The final theme that emerged involved psychological factors. These psychological factors include acceptance of their current condition and future implications and changing their mindset is important for self-management. The patients indicated that they had issues with accepting their stroke and the resulting impairments. They felt that self-management addressed these factors, by facilitating a change in their attitude towards their condition and providing a platform for addressing these issues. A Meta-review of qualitative systematic reviews by Pearce et al. (2015) found that emotional and psychological support are important factors when coming to terms with the patient's situation post stroke.

The reference to psychological factors is an important component as psychological status impacts on the recovery of patients. Patients who are psychologically impaired have a decreased ability to engage in self-management programmes (Parke et al., 2015). They would then have an increased dependency on caregivers. A qualitative study by Murphy et al. (2015), found that patients often face many struggles with effective self-management. These struggles include poor health literacy, lack of self-efficacy and lack of apparent social support.

It is therefore important to note that stroke survivors feel that psychological factors would affect how they self-manage and form a big part of what self-management is. Psychological factors can further influence the independence which stroke survivors seek and associate with self-management. Self-management strategies can provide stroke patients with a platform to achieve acceptance of their condition post stroke (Jones, Riazi & Norris, 2012), as well as giving them an

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opportunity to define their goals and plan for the future (Satink et al., 2015), thus empowering them further.

5.2 THE PARTICIPANTS' VIEWS ON WHETHER A SELF-MANAGEMENT PROGRAMME IS APPROPRIATE IN A LOCAL (SOUTH AFRICAN) SETTING/CONTEXT

This question addressed the last objective of this study, which was to explore HCPs' and stroke patients' perceptions regarding the integration of self-management strategies into current rehabilitation programmes. Both the patients and HCPs felt that the addition of a self-management programme to an already established rehabilitation program would be beneficial in a local context. However, the HCPs felt that, even though a self-management program could work in a local context, many barriers would have to be overcome. These barriers derived from government and rehabilitation resources, South Africa's socio economic background and patients' dependence on HCPs.

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5.2.1 The HCPs' and patients' views on whether a self-management programme could work in a local (South African) setting/context

This section will be discussed in terms of the identified barriers and this is followed by a discussion of the positive factors of the implementation of a SMP into a rehabilitation program.

5.2.1.1 Possible barriers to the implementation of a SMP

During the focus group discussions, the HCPs stressed that the lack of government and rehabilitation resources and the already heavy burden on the health system could hinder the implementation of such a programme. They mentioned that, once patients were discharged back into the community and had to attend out-patient therapy sessions, the physical resources (too few

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therapists, inadequate space, etc.) and long waiting periods between sessions presented barriers to successful implementation. Jordan and Osbourne (2007) found that poor service delivery as a result of inadequate state funding impacted the implementation of self-management programmes.

The HCPs did feel that the success of any implementation would depend on correct implementation and follow through.

The HCPs also noted that South Africa's socio economic background could possibly affect the implementation of a SMP in a local context. The levels of literacy and many cultural differences and sensitivities could hinder the effectiveness of such programmes. If the patient is unable to engage (literacy) or relate (cultural differences) with the self-management material (notes or illustrations), the effectiveness of the SMP could be questioned.

The history of South Africa plays a huge role in the implementation of self-management. Many inadequacies due to the apartheid regime exist among the diverse populations of the country. There are still educational and financial barriers that separate much of the population; these include access to adequate medical care and rehabilitation. There are at least 11 official languages in South Africa, with many, if not more, varying cultures, each with their own sensitivities and traditions that must be taken into account when implementing such a programme, therefore one cannot assume a "one size fits all" approach. Financial support in low socioeconomic brackets can lead to inadequate care post discharge. In many cases families cannot afford to hire carers or stay at home to become the carer because of financial constraints. In many cases, the patient/stroke survivor had been the bread winner in the family. Implementing a self-management programme would assist these families as this programme could facilitate patients managing themselves at home. Low literacy levels often impact the effectiveness of source materials and the understanding of complex programs. Dube et al. (2014), found that it is important to take the levels of literacy

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into consideration when planning SMPs as well as the financial constraints that affect patients' self-care (Liddy, Blazkho & Mill, 2014; Muchiri, Gericke & Rheeder, 2012).

These barriers are similar to what was found by Norris, Jones, Kilbride and Victor (2014), namely that cultural and ethnic barriers and dependence on HCPs (Sadler, 2017; Samuel-Hodge et al,, 2000) present a significant portion of self-management. Mudge et al. (2014) stated that it is important to take the complexities of people's lives in consideration when implementing a self-management plan.

The HCPs furthermore commented that stroke survivors remain very dependent on the advice and support of HCPs for their rehabilitation, both emotionally and physically. For the implementation of a SMP to be effective, both HCPs and patients will need to change their mindsets and have trust in the self-management process.

5.2.2 Implementation of a self-management program as part of a rehabilitation programme

Although the HCPs felt that there would be many barriers when implementing a SMP into a rehabilitation program, they did highlight that a SMP could assist in alleviating the existing rehabilitation pressures which include financial constraints, transport to the clinic for follow-up and sessions and the issuing of assistive devices. The HCPs all agreed that the implementation of a SMP could really motivate and promote the self-confidence of stroke survivors. They noted that the features of a SMP such as the monitoring or recording of a patient's progress can positively impact a stroke survivor, thus providing motivation to further improve on their skill set. Due to this, it is important for HCPs to empower stroke survivors by giving them the tools to identify and set goals for themselves – goals that are important and significant to them (Kidd et al., 2015;

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Dixon, Thornton & Young., 2007; Hirsche et al, 2011). The HCPs did feel that the success of any implementation would depend on correct implementation and follow through.

Both the patients and the HCPs felt that a self-management programme would assist stroke survivors in gaining the necessary knowledge about the condition and resulting impairments, by providing guidelines encouraging them to be more active in their rehabilitation progress and do more to help themselves. Catalano, Dickson, Kendall, Kuipers and Posner (2003) conducted a qualitative study in Australia that study noted similar findings. They found that patients who were exposed to a self-management program felt a sense of improved motivation and accomplishment. McKenna et al. (2015) also found that patients felt that a self-management programme would assist them in managing progress, goal setting and ownership of their condition.

The stroke patients further felt that a self-management programme would assist them in taking responsibility for their current condition and recovery process, while also acting as a motivating factor. By accepting help, but not becoming dependent on those who provided the assistance to be a factor, they felt that a SMP can be made possible by the provision of guidelines and support by HCPs. The HCPs also felt that a self-management programme can help stroke survivors to adapt to their situation post stroke, thus aiding their ability to cope and learn in order to adapt to their new reality during the transition from hospital to home life. From their qualitative study. Boger et al. (2015) concluded that the "presence of external support and an environment which supports and facilitates people following stroke to self-manage" was beneficial.

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CHAPTER 6: SUMMARY, LIMITATIONS, CONCLUSION, SIGNIFICANCE OF THE STUDY AND RECOMMENDATIONS

6.0 INTRODUCTION

In this final chapter, a general summary of the study is presented. The conclusion that is presented highlights prominent findings and the limitations of the study are discussed. To conclude this section, the significance of and recommendations that emerged from the study are presented.

6.1 SUMMARY OF THE STUDY

The aim of this study was to explore the perceptions of Health Care Professionals and stroke patients in the Western Cape with regard to self-management in two facilities in the Western Cape. A descriptive, exploratory design within a qualitative research approach was used in order to investigate the objectives of the study which were to explore the HCPs' and stroke patients' understanding of the concept of self-management; to explore HCP perceptions of the application of self-management strategies by stroke survivors; and to explore HCPs' and stroke patients' perceptions regarding the integration of self-management strategies into current rehabilitation programmes. The study comprised two parts; part one consisted of focus group discussions with HCPs; and part two of the study involved in-depth interviews with stroke patients. The qualitative results showed that participants in both parts of the study were not able to explain self-management clearly, but were able to communicate the main aspects of self-management. They felt that a self-management programme would work in a South African context, although participants felt that certain aspects could act as barriers and impact the implementation of self-management in stroke patients in the Western Cape.

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6.2 LIMITATIONS OF THE STUDY

- Although almost the entire population of HCPs at BMH was used, the population and study sample was significantly smaller than that at LEIC. Therefore, although saturation was reached during the first focus group, the data set could have been richer.
- Patients with cognitive or communication difficulties were excluded from the interview population, therefore, the study population may only represent a certain collection of views which might not necessarily be the views of those with cognitive or communication difficulties post stroke.
- The patients were screened and selected by the head of therapy at BMH and a formal cognitive assessment, such as a mini-mental, was not performed by the researcher or independent researcher to confirm cognitive status.
- Patient representation was only from one hospital, although patients are admitted from across the Western Cape with diverse backgrounds, not all categories of patient were represented, therefore this study is not representative of the Western Cape as a whole.

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6.3 CONCLUSION

The aim of this study, to explore the perceptions of Health Care Professionals and stroke patients in the Western Cape about self-management in two facilities in the Western Cape was achieved. The study gave the researcher insight into the HCPs' and patients' perceptions of what their interpretation of self-management was, as well as whether they thought it could be implemented in a local setting. The study showed that, although the participants had a basic concept of what self-management entailed, they still did not fully grasp the term. Participants felt that a self-

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management programme could work when implemented as part of a rehabilitation programme; they felt it would have a positive effect on their outcomes. Although all participants were positive that a self-management programme for stroke survivors could work in South Africa, there some barriers were also highlighted. These barriers included patients' psychological status, the country's socioeconomic climate, government resources and cultural differences. It is vital to note that these barriers should be addressed when considering facilitating self-management or developing self-management programmes in the future.

6.4 SIGNIFICANCE OF THE STUDY

Not much research has been done in South Africa, specifically the Western Cape, on self-management following a stroke. The findings of this study are therefore important for all stakeholders (policy makers, researchers and clinicians) when looking at the implementation and development of self-management programmes post stroke. This study provides a reliable source of information, especially for clinicians and researchers who want to include and adapt self-management strategies in their pre-existing rehabilitation programmes. The study also serves as a source of information for policy makers and researchers regarding the barriers that stroke patients and HCPs perceive as possible hindrances to the implementation of a successful stroke self-management programme, which should therefore be addressed. The findings of this study could furthermore facilitate successful self-management practice.

6.5 RECOMMENDATIONS

The following recommendations are suggested on basis of the findings of this study:

1. Although all the participants expressed similar views/perceptions of self-management, the study was based in the public sector, therefor providing insight only from a certain

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socioeconomic aspect (health care professionals all worked in the public sector). More research should be focused on both in-patient and out-patient stroke survivors' perceptions of self-management and self-management programs in a private setting in the Western Cape, in order to further deepen and diversify the current research.

2. The barriers that emerged when discussing whether a self-management programme could work when implemented as part of a rehabilitation programme in a local setting, can inform researchers and policy makers when adapting or developing self-management strategies or programmes for stroke survivors, especially in a local context. These barriers are paramount when considering successful implementation of such programmes, especially in lower socioeconomic groups/areas.
3. They study showed that clinicians feel that self-management is important and can aid in the successful rehabilitation of stroke survivors; they should therefore receive training in and be encouraged to employ self-management strategies in their rehabilitation programmes with their stroke patients, in both out- and in-patient settings.
4. There is proof that self-management can assist in relieving some of the burden on health care systems; this study shows that both HCPs and stroke patients feel that a self-management programme can work in a local setting, when implemented into a rehabilitation programme. Government and policy makers should therefore consider implementing such strategies as part of the care package for stroke patients.
5. Although the stroke patients in this study represented some of the population of the Western Cape, it is important to acknowledge the many diverse cultures, populations and languages of this area. Further research regarding self-management therefore is needed in order to consider these additional factors, thus enriching the quality of the data.

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APPENDIX 1

UNIVERSITY OF THE WESTERN CAPE

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Revised: December 2015

INFORMATION SHEET: Healthcare Professionals

Project Title: Perceptions of healthcare professionals and stroke patients regarding self-management programmes.

What is this study about?
This is a research project being conducted by Renée Jansen at the University of the Western Cape for this study. The purpose of this research project is to explore the perceptions healthcare professionals and stroke patients have about self – management programs and whether it will be applicable in a local setting.

What will I be asked to do if I agree to participate?
You will be asked to participate in a focus group discussion or have a one on one interview. This research project involves making audiotape recordings of you. The recordings will be made in order to verify information during the study. You will be given a transcription of the data to verify that the information you gave is correct.

- The focus group discussion or interview will take place at your facility (Booth Memorial Hospital or Life Esidimeni Intermediate Care).
- The date, time and venue will be communicated to you.

Would my participation in this study be kept confidential?
The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity:
(1) Your name will not be included on the collected data
(2) A code will be placed on the collected data
(3) Through the use of an identification key, the researcher will be able to link your survey to your identity
(4) Only the researcher will have access to the identification key.

To ensure your confidentiality, all transcribed data will be stored in locked filing cabinets, any electronic information will be stored using password – protected computer files. This data will not contain your particulars, it will be coded.

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If we write a report or article about this research project, your identity will be protected.

This study will use focus groups therefore the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

What are the risks of this research?
All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?
This research is not designed to help you personally, but the results may help the investigator learn more about healthcare professionals and stroke patients' perceptions of self - management. We hope that, in the future, other people might benefit from this study through improved understanding of self - management.

This research may assist in decreasing the burden on an already financially stressed health system that operates on few resources while also assisting the local population with autonomy, by taking charge of their health and well-being. The findings can facilitate research on this topic and assist with development of a stroke self-management programme.

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Do I have to be in this research and may I stop participating at any time?
Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?
This research is being conducted by Renée Jansen from the Physiotherapy Department, at the University of the Western Cape. If you have any questions about the research study itself, please contact Renée Jansen at:
Booth Memorial Hospital, Oranjezicht, Cape Town.
021 465 4846
reneej@boothhosp.org

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the University of the Western Cape's Research Ethics Committee. (REFERENCE NUMBER: HS16/5/40).

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APPENDIX 2

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Revised: December 2015

INFORMATION SHEET: Stroke patients

Project Title: Perceptions of healthcare professionals and stroke patients regarding self-management

What is this study about?

This is a research project being conducted by Renée Jansen at the University of the Western Cape for this study. The purpose of this research project is to explore the perceptions healthcare professionals and stroke patients have about self – management programs and whether it will be applicable in a local setting.

What will I be asked to do if I agree to participate?

You will be asked to participate in a focus group discussion or an interview. This research project involves making audiotape recordings of you. The recordings will be made in order to verify information during the study. You will be given a transcription of the data to verify that the information you gave is correct.

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All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?
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This research may assist in decreasing the burden on an already financially stressed health system that operates on few resources. While also assisting the local population with autonomy, by taking charge of their health and well - being. The findings can facilitate research on this topic and assist with development of a stroke self – management programme.

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Do I have to be in this research and may I stop participating at any time? Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

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Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the University of the Western Cape's Research Ethics Committee. (REFERENCE NUMBER: HS16/5/40)

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APPENDIX 3

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Hersien: Desember 2015

INLIGTINGSBLADSY : Beroerte pasiënte

Projek Titel: Persepsies van professionele gesondheidswerkers en beroerte pasiënte met betrekking tot self-bestuur.

Waaroor gaan hierdie studie??
Hierdie navorsingsprojek word deur Renée Jansen aan die Universiteit van Wes-Kaapland uitgevoer. Die doel van hierdie navorsingsprojek is om die persepsies van gesondheidswerkers en pasiënte met beroerte te ondersoek oor selfbestuursprogramme en of dit in 'n plaaslike omgewing van toepassing kan wees.

Wat sal ek gevra word om te doen as ek meedoen om deel te neem?
U sal gevra word om deel te neem aan 'n fokusbesprekinggroep of 'n onderhoud. Hierdie navorsingsprojek behels die maak van oudio-opnames van jou. Die opnames sal gemaak word om inligting tydens die studie te verifieer. U sal 'n transkripsie van die data kry om te verifieer dat die inligting wat u verskaf het korrek is.

- Die fokusbesprekinggroep of onderhoud sal by u fasiliteit plaasvind (Booth Memorial Hospitaal of Life Ensedimeni Intermediêre Sorg).
- Die datum, tyd en plek sal aan u gekommunikeer word.

Sal my deelname aan hierdie studie vertroulik gehou word?
Die navorsers onderneem om u identiteit en die aard van u bydrae te beskerm.
Om vertroulikheid van die versamelde data te verseker:

(1) Jou naam sal nie op die versamelde data ingesluit word nie
(2) 'n Kode sal op die versamelde data geplaas word
(3) Deur die gebruik van 'n identifikasie sleutel kan die navorser jou opname koppel aan jou identiteit
(4) Slegs die navorser sal toegang tot die identifikasie sleutel hê.

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Om u vertroulikheid te verseker sal alle getranskribeerde data gestoor word in geslote liasseringskaste, enige elektroniese inligting sal gestoor word deur gebruik te maak van wagwoordbeskermde rekenaarlêers. Hierdie data bevat nie u besonderhede nie, dit sal gekodeer word.
As ons 'n verslag of artikel oor hierdie navorsingsprojek skryf, sal u identiteit beskerm word.
Hierdie studie sal fokusgroepe gebruik, daarom is die mate waarin u identiteit vertroulik bly, afhanklik van deelnemers in die fokusgroep wat vertroulikheid handhaaf.

Wat is die risiko's van hierdie navorsing?
Alle menslike interaksies en praat oor self of ander dra 'n mate van risiko's. Ons sal egter sulke risiko's verminder en dadelik optree om u te help as u enige ongemak, sielkundige of enige ander ervaar tydens die proses van u deelname aan hierdie studie. Waar nodig, sal 'n gepaste verwysing gemaak word en na 'n geskikte professionele persoon vir verdere bystand of ingryping gestuur word.

Wat is die voordele van hierdie navorsing?
Hierdie navorsing is nie ontwerp om u persoonlik te help nie, maar die resultate kan die ondersoeker help om meer te leer oor gesondheidswerkers en beroerte pasiënte se persepsies van selfbestuur. Ons hoop dat ander mense in die toekoms dalk baat sal vind by hierdie studie deur beter begrip van selfbestuur.
Hierdie navorsing kan help om die las op 'n reeds finansieel gestremde gesondheidstelsel wat op min hulpbronne werk, te verminder. Terwyl die plaaslike bevolking ook met outonomie help word, deur beheer oor hul gesondheid en welsyn te neem. Die bevindings kan navorsing oor hierdie onderwerp fasiliteer en help met die ontwikkeling van 'n beroerte selfbestuursprogram.

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Moet ek in hierdie navorsing wees en mag ek op enige stadium ophou deelneem?
U deelname aan hierdie navorsing is heeltemal vrywillig. U mag kies om glad nie deel te neem nie. As u besluit om aan hierdie navorsing deel te neem, kan u enige tyd ophou deelneem. As u besluit om nie aan hierdie studie deel te neem nie, of as u op enige stadium ophou deelneem, sal u vir nie enige voordele wat u andersins kwalifiseer, gepenaliseer word nie of verloor.

Wat as ek vrae het?
Hierdie navorsing word deur Renée Jansen van die Fisioterapie Departement, aan die Universiteit van Wes-Kaapland, uitgevoer. As jy vrae het oor die navorsingstudie self, kontak asseblief vir Renée Jansen by:
Booth Memorial Hospitaal, Oranjezicht, Kaapstad.
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Indien u enige vrae rakende hierdie studie en u regte as 'n navorsingsdeelnemer het of as u enige probleme rakende die studie wil aanmeld, kontak asseblief:

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Prof José Frantz
Dekaan van die Fakulteit Gemeenskap- en Gesondheidswetenskappe
Universiteit van Wes-Kaapland
Privaatsak X17
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Hierdie navorsing is deur die Universiteit van Wes-Kaap se Navorsingsetiekkomitee goedgekeur. (VERWYSINGSNOMMER: HS16/5/40).

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

APPENDIX 4

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217
E-mail: reneej@boothhosp.org

FOCUS GROUP CONFIDENTIALITY BINDING FORM

Title of Research Project: Perceptions of healthcare professionals and stroke patients regarding self-management.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone by the researchers. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality.

I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Participant's name……..

Participant's signature……..

Date……

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APPENDIX 5

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2542, Fax: 27 21-959 1217
E-mail: reneej@boothhosp.org

CONSENT FORM: Stroke Patients

Title of Research Project: Perceptions of healthcare professionals and stroke patients regarding self-management programmes

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

___ I agree to be audiotaped during my participation in this study.
___ I do not agree to be audiotaped during my participation in this study.

Participant's name……..

Participant's signature…….

Date……

http://etd.uwc.ac.za/

APPENDIX 6

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
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TOESTEMMINGSVORM: Beroerte-pasiënte

Titel van navorsingsprojek: *Persepsies van gesondheidsorgpersoneel en beroertepasiënte ten opsigte van selfbestuursprogramme*

Die studie is aan my beskryf in 'n taal wat ek verstaan. My vrae oor die studie is beantwoord. Ek verstaan wat my deelname sal behels, en ek stem in om deel te neem uit eie keuse en vrye wil. Ek verstaan dat my identiteit aan niemand bekend gemaak sal word nie. Ek verstaan dat ek te eniger tyd aan die studie kan onttrek sonder om 'n rede te gee en sonder vrees vir negatiewe gevolge of verlies aan voordele.

___ Ek stem in dat tydens my deelname aan hierdie studie,'n oudioband opgeneem kan word.

___ Ek stem nie saam dat tydens my deelname aan hierdie studie,'n oudioband opgeneem kan word nie.

http://etd.uwc.ac.za/

Deelnemer se naam ……..

Deelnemer se handtekening …….

Datum……

http://etd.uwc.ac.za/

APPENDIX 7

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E-mail: reneej@boothhosp.org

CONSENT FORM

HEALTH CARE PROFFESIONALS – FOCUS GROUP

Title of Research Project: Perceptions of healthcare professionals and stroke patients regarding self-management.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

___ I agree to be audiotaped during my participation in this study.
___ I do not agree to be audiotaped during my participation in this study.

Participant's name……..

Participant's signature…….

Date……

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APPENDIX 8

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FOCUS GROUP DISCUSSION GUIDE FOR HEALTH CARE PROFESSIONALS

1. Tell me what self-management means:

Probes:

- To yourself

2. Do you think it'll work of incorporated into a rehabilitation programme?

Probes:

- In South Africa
- In local setting

If yes or no, why?

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APPENDIX 9

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E-mail: reneej@boothhosp.org

ENGLISH INTERVIEW GUIDE FOR STROKE PATIENTS

1. Tell me what self-management means:

Probes:

- To you

2. Do you think self – management will work when incorporated into a rehabilitation programme?

Probes:

- In South Africa
- In local setting
-

If yes or no, why?

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APPENDIX 10

UNIVERSITEIT VAN WES-KAAP

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Tel: +27 21-959 2542, Faks: 27 21-959 1217
E-pos: reneej@boothhosp.org

ONDERHOUDGIDS VIR BEROERTEPASIËNTE

1. Vertel my wat selfbestuur beteken:

Ondersoek:

- Vir jou

2. Dink jy dit sal werk as deel van ‘n rehabilitasie program?

Ondersoek:

- In Suid-Afrika
- In ‘n plaaslike omgewing

Indien ja of nee, hoekom?

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

UNIVERSITY of the WESTERN CAPE

OFFICE OF THE DIRECTOR: RESEARCH
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12 September 2016

Ms R Jansen
Physiotherapy
Faculty of Community and Health Science

Ethics Reference Number HS16/5/40

Project Title: Perceptions of healthcare professionals and stroke patients regarding self-management.

Approval Period: 07 September 2016 _ 07 September 2017

I hereby certify that the Humanities and Social Science Research Ethics Committee of the University of the Western Cape approved the methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

PROVISIONAL REC NUMBER - 130416-049