

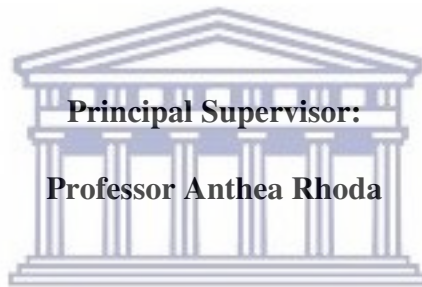
**SELF-MANAGEMENT STRATEGIES EMPLOYED BY  
STROKE SURVIVORS IN THE WESTERN CAPE, SOUTH AFRICA**

**By**

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**A full thesis submitted in partial fulfilment of the requirements for the degree of  
Master of Science in the Department of Physiotherapy, University of the  
Western Cape.**



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## KEYWORDS

Stroke

Self-Management

Rehabilitation

Social Cognitive Theory

The International Classification of Functioning, Disability and Health

Activity Limitations

Participation Restriction

Environmental Challenges

South Africa

Exploratory Design



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## ABSTRACT

Ischaemic heart disease and stroke were the leading causes of death and disability globally, accounting for a combined 15 million deaths. Disability following a stroke is complex and multidimensional. Disability and functioning post stroke can be conceptualized within the framework of the International Classification of Functioning, Disability and Health (ICF). The involvement of the individual in their rehabilitation and recovery is essential. Therefore, it is a necessity for individuals, particularly in a low resource setting to engage in self-management activities. Bandura's social cognitive theory based on self-efficacy, forms the basis of self-management programmes. Self-management relates to one's ability to manage one's consequences post stroke, and self-efficacy has been proven to be pivotal in the management and improvement of long-term conditions. The aim of the study was to explore the self-management strategies employed by stroke survivors in the Western Cape, South Africa through an exploratory, qualitative design. Prior to the commencement of the data collection phase, ethical clearance was sought from the University of the Western Cape Research Ethics Committee. Participants were recruited from an urban and rural area in the Western Cape. An interview guide was developed based on previous literature. Interview questions were related to 1) what self-management strategies were adopted to address activity limitations and participation restrictions and 2) strategies used to address environmental challenges.

An in-depth interview with probing questions was conducted to collect the experiences of the stroke survivors and a total of 14 participants were interviewed. The participants' interviews were audiotaped during the interview process. Their audiotapes were then transcribed verbatim. The interviews that were conducted in Afrikaans were transcribed and then subsequently translated into English. Braun and Clarke's 6 step thematic analysis was used to

analysis the data. Trustworthiness of the analysis was addressed by establishing credibility, transferability, dependability and confirmability.

The results found that participants exhibited four main encompassing strategies to facilitate their recovery. There were four main themes that emerged from the data, namely: adaptation, engaging with information, coping and acceptance strategies, and exercise to facilitate recovery. The sub-themes identified within the theme of adaptation were: 1) changing traditional formats, 2) modification of the task and 3) new functioning formats. The sub-themes identified within the theme of engaging with information were: 1) finding similar others, 2) information provided by health professionals and 3) traditional remedies. The sub-themes identified within the theme of coping and acceptance strategies were: 1) spirituality, 2) support systems and self-efficacy. The sub-themes identified within the theme exercise to facilitate recovery included: 1) daily structured exercise and 2) exercise to address impairments.

Stroke survivors exhibit multiple strategies to remain independent and facilitate functioning, mainly at the level of activity limitations. The findings of this study are more related to higher functioning stroke survivors as ten out of fourteen of the participants of the study were ambulatory. To function within the community and their home environment stroke survivors implement adaptive behaviours, engage with information from various sources, depend on a higher power and exercise to address their impairments and subsequently facilitate their recovery. Self-management strategies employed by newly affected persons with stroke should be considered, supported and integrated into the rehabilitation of these individuals.

# DECLARATION

I declare that: “**Self-management strategies employed by stroke survivors in the Western Cape, South Africa**”, is my own work, that it has not been submitted for any degree or examination at any other university, and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.

Signature:.....

Date:.....

**Janine Lynette Smith**

**Witness:**

.....

Professor Anthea Rhoda



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To my dance teachers, Renee Roman and Lindsey Van Niekerk and my high school English Teacher, Asha Lalla, thank you for moulding me and guiding me into the woman I am today. "Phenomenal women are we".

A special thank you to the authors, Enid Blyton, Tim Bowler, J.K. Rowling and Lewis Carroll for creating worlds of wonder and curiosity. Reading their works has been a constant form of encouragement during my studies and throughout my life.

## DEDICATION

I dedicate my thesis to my late grandmother. Granny Valda Doreenia Smith, thank you for teaching me that great strength and growth comes only through continuous effort and struggle. I love you. I miss you. RIP.



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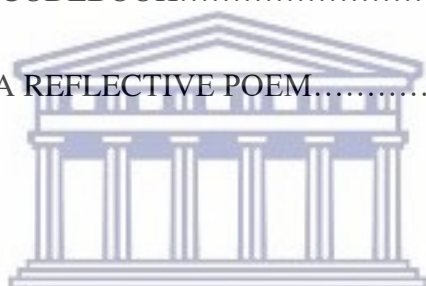
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## LIST OF ABBREVIATIONS

ADLs	Activities of Daily Living
DALYs	Disability-Adjusted Life-Years
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
ICF	International Classification of Functioning, Disability and Health
ICU	Intensive Care Unit
KM	Kilometres
LEIC	Life Esidimeni Intermediate Care
MPDH	Mitchells Plain District Hospital
NICE	National Institute for Health and Clinical Excellence
RA	Rheumatoid Arthritis
RCWs	Rehabilitation Care Workers
RHAP	Rural Health Advocacy Project
SA	South Africa
SCT	Social Cognitive Theory
SSMP	Stroke Self-Management Programme
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UWC	University of the Western Cape
WCRC	Western Cape Rehabilitation Centre

WHO

World Health Organization



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# CHAPTER 1

## INTRODUCTION

### 1.1 INTRODUCTION

The introductory chapter will firstly present a description of stroke and the burden of stroke. The conceptual framework for the study will be highlighted. The activity limitations and the participation restrictions post stroke will be presented. The concept of self-management and self-efficacy will be introduced and how this relates to rehabilitation post stroke. The problem statement will be discussed. The research question, aim, and objectives of the study will also be presented.

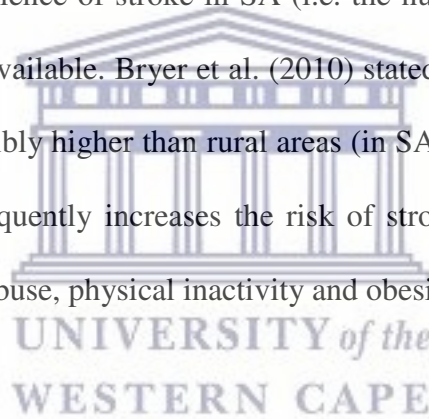


### 1.2 BACKGROUND

Stroke was defined in the 1980s by the World Health Organization 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, 1988). Much attention is placed on stroke research all over the globe, as identified by Feigin, et al., (2014) due to its devastating consequences. In 2015, ischaemic heart disease and stroke were the leading causes of death globally, accounting for a combined 15 million deaths (WHO, 2017), and these diseases have remained the leading causes of death globally in the last 15 years. According to the Global Burden of Disease Report, among people aged 60 years and older stroke is the second leading cause of death worldwide (Lozano, Naghari, & Foreman, 2012) and globally. The absolute number of people having a stroke worldwide is increasing, due to an ageing population. It equates to one in six people around the world having a stroke in their lifetime (Thrift et al., 2014; WHO, 2004).

Two thirds of all stroke deaths occur in developing regions, such as sub-Saharan Africa, although after the Human Immunodeficiency Virus (HIV) and ischaemic heart disease, stroke is considered to be the third most common cause of death in SA. Stroke is also the most common cause of death in people over 50 years of age in SA (Bryer et al., 2010). An estimated 75 000 strokes occur in SA every year. Of these, 25 000 stroke survivors die within the first month (Bertram, Katzenellenbogen, Vos, Bradshaw, & Hofman, 2013). Also, according to the SA Heart and Stroke foundation 240 strokes occur daily in SA (Bryer et al., 2010).

Accurate figures on the prevalence of stroke in SA (i.e. the number of stroke survivors at a given time), are presently unavailable. Bryer et al. (2010) stated that the prevalence of stroke in urban areas (in SA) is possibly higher than rural areas (in SA) due to a greater exposure to lifestyle factors, which subsequently increases the risk of stroke. Lifestyle factors include: smoking, alcohol, substance abuse, physical inactivity and obesity.



As described above stroke is a major cause of death and disability worldwide (Feigin, Lawes, Bennett, Barker-Collo, & Parag, 2009). The true burden of stroke does however not lie in the high mortality rate alone, but rather in combination with the high morbidity rate, whereby up to 50% of participants with stroke are left chronically disabled (Connor & Bryer, 2006). Often the majority of survivors experience some degree of impairment which typically requires additional care (Horgan, O'Regan, Cunningham, & Finn, 2009). The long-term impacts of stroke for the individual include among other things, social isolation, mood disturbances, decreased community involvement, disruption of family functioning, poor

motivation, dependency, reduction in mobility and life roles, and loss of control (McKevitt et al., 2011; Murray, Young, & Forster, 2009).

Disability following a stroke is complex and multidimensional, involving biomedical, psychological and sociological elements. Typically, the range of activities and social roles previously performed are difficult to maintain following stroke (Ellis-Hill, Payne, & Ward, 2008; Ch'ng, French, & Mclean, 2008; Mukherjee, Levin, & Heller, 2006).

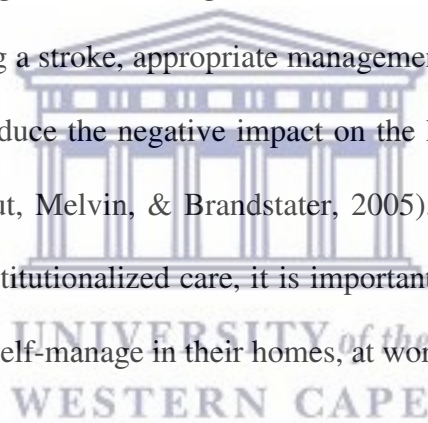
Disability and functioning post stroke can be conceptualized within the framework of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The components of the ICF can be used to indicate problems with regard to disability, such as impairments, activity limitations or participation and functioning restrictions (WHO, 2001). Following a stroke, participants may experience activity limitations and participation restrictions. Activity limitations are difficulties in performing the activities of daily living (ADLs) (WHO, 2001). Participation refers to the ability of people to manage the roles and responsibilities they were previously performing (WHO, 2001). In addition to activity limitations and participation restrictions, stroke survivors also experience a number of barriers to their participation and activity. The physical environment poses the most common barrier for people with physical disabilities (O'Donovan, Doyle, & Gallagher, 2009).

Rehabilitation is the process through which the disability experienced by stroke survivors is addressed. The rehabilitation of stroke participants includes early physical, occupational and speech therapy, facilitating re-integration of stroke participants into their communities (community re-integration), education of participants and their families about stroke and prevention of further complications (SIGN, 2010). The involvement of the individual in their

rehabilitation and recovery process is important. The employment of self-management strategies which is linked to the individual's involvement in the management of their conditions is fundamental and a lack of patient engagement could negatively impact their recovery post stroke (Kristensen, Tistad, Koch, & Ytterberg, 2016). (Lorig & Holman, 2003). Furthermore, self-management is cited as a means of empowerment and facilitator of improved health outcomes (Battersby et al., 2010; Kralik, Koch, Price, & Howard, 2004). Engagement in self-management strategies or practices has been suggested as one key element to promoting recovery (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). The concept of self-management has always existed, whether through self-help groups, family or community support (Kendall & Rogers, 2007). The concept of self-management, which is based on self-efficacy principles, has been found to have a positive effect on quality of life since those with greater self-efficacy are better equipped to tackle their unmet needs by utilizing resources in their existing environment. The principle of self-efficacy is one of the four processes, (self-observation, self-evaluation, self-reaction and self-efficacy), of goal realization of Bandura's social cognitive theory (Bandura, 1989). The components of the four processes are interrelated, each having an effect on motivation and goal attainment (Redmond, 2010). Bandura's social cognitive theory will be explored further in chapter 2.

In rehabilitation literature self-efficacy is viewed through various concepts such as: self-management, autonomy, choice and control. The definitions for self-management, autonomy, choice and control can be conceptualized in Bandura's social cognitive theory (1989) and these terms relates to people being able to manage the devastating consequences for disease if they are aware of the services offered and have knowledge on how to manage their disease. From this point onwards, self-management will be used as the operational definition.

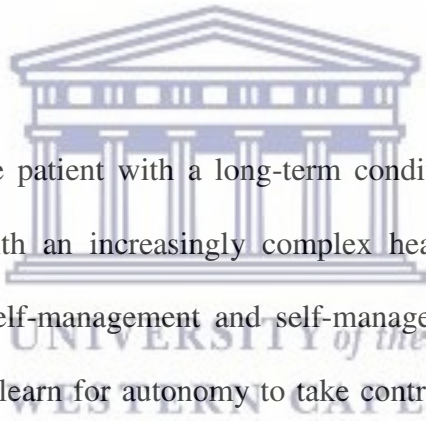
Self-management encompasses the patient's ability to monitor their condition and to apply the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Self-management is best realized when the individual who suffers from a chronic illness, and health care provider work together in successful partnership (Barlow, Wright, Sheasby, Turner, & Haninsworth, 2002). For people with a long-term condition such as stroke, adjustments such as modifying one's lifestyle and/or learning new behaviours becomes a inevitability. However, the ease with which such changes occur is multifaceted due to individual risk factor control and life risk factor control (for example, physical activity, diet and nutrition, stress management, smoking, alcohol and medical adherence) (Sakakibara, Kim, & Eng, 2016). Following a stroke, appropriate management during the acute period will result in less disability and reduce the negative impact on the health care sector and society (McNaughton, de Jong, Smout, Melvin, & Brandstater, 2005). Therefore, since the goal of rehabilitation goes beyond institutionalized care, it is important that clients with a stroke are empowered with the skills to self-manage in their homes, at work and at play.



South Africa has limited resources for health care and even more limited resources to rehabilitative services (Stanmore & Waterman, 2007). So, the question remains, how are participants managing post hospitalization? How are participants coping in their home environments? What are the strategies that participants use to adapt and survive? What are the strategies that participants employ to define new functioning frameworks?

### 1.3 PROBLEM STATEMENT

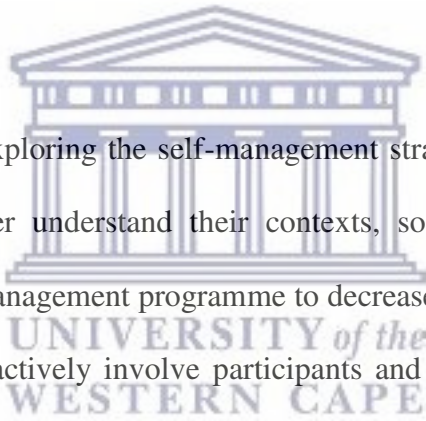
Rehabilitation plays an essential role in minimizing the impact of impairments on the activities of daily life (ADLs) and participation of persons with disabilities in their communities (WHO, 2011). Stroke survivors indicated that rehabilitation was physically driven and lacked social and psychological inputs (Benz, 2003; Murray, Young, Forster, & Ashworth, 2003; McKeivitt et al., 2004; Peoples, Satink, & Steultjens, 2011). Issues and challenges have also been identified with the way in which goals are set with rehabilitation professionals, lack of awareness about local services for support, and inadequate long-term contact with the rehabilitation teams (Murray et al., 2003). A lack of active involvement of the patient in the rehabilitation process has also been noted.



Self-management involves the patient with a long-term condition working to manage their condition in collaboration with an increasingly complex health- and social-care network (Creer, & Holroyd, 2006). Self-management and self-management support are two of the methods that participants can learn for autonomy to take control of their recovery. Effective self-management is often dependent on the collaboration between the patient and the physiotherapist. It is this collaborative approach that helps the patient to acquire the skills and confidence to manage their condition (Cooper, Smith, & Hancock, 2009). Self-management strategies form an important part of physiotherapy treatment plans because participants will spend more time away from the physiotherapist than receiving clinic- or hospital-based care (Peek, Sanson-Fisher, Macklenzie, & Carey, 2016).

By investigating self-management strategies, we are therefore in a position to evaluate the functioning priorities of persons with a stroke in South Africa, but the investigation of self-

management strategies to address activity limitations and participation restrictions, could also elucidate other functioning needs that persons with stroke cannot manage themselves. In order for therapists to implement self-management support therapists need to be acutely aware of the self-management strategies that stroke survivors employ post stroke. Only once equipped with this information will therapists be able to make patient-informed decisions to improve and promote recovery post stroke. Current literature on the topic of self-management in stroke rehabilitation has been conducted in developed countries, namely the United States of America, United Kingdom, and New Zealand (Hale et al., 2014; Lorig, Holman, Sobel, Laurent, González, & Minor, 2012; McKenna, Jones, Glenfield, & Lennon, 2015). Limited information is available for South Africa.



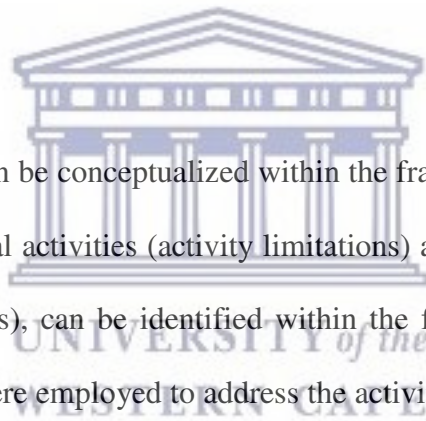
This research will focus on exploring the self-management strategies used by persons living with stroke in order to better understand their contexts, so that future research can be conducted to develop a self-management programme to decrease the burden on the health care system. For professionals to actively involve participants and caregivers, knowledge of the experiences of these individuals is essential but lacking in current literature. There is a need for participants to be involved in the management of their conditions to facilitate their recovery which could decrease the strain on the health care system.

#### **1.4 CONCEPTUAL FRAMEWORK: INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH**

Functioning post stroke can be conceptualized within the framework of the International Classification of Functioning, Disability and Health (ICF). The ICF is endorsed by WHO (WHO, 2001) and provides a standardized and unified framework for the description of health



and health-related states (Brogardt & Lexell, 2015). In the biopsychosocial model proposed in the ICF, functioning is defined as a continuum that encompasses two components, body functions and structures, and activities and participation, and is determined by interactions between health conditions and contextual factors (environmental and personal factors) (Cieza, Bickenbach, & Chatterji, 2008; WHO, 2001). The National Institute for Health and Clinical Excellence (NICE) noted that stroke is the single largest cause of complex physical and cognitive impairment, with most participants living with moderate to severe chronic impairment, activity limitation and participation restrictions, as a result (NICE, 2010). The ICF is therefore useful for evaluating the patient's problems post stroke as well as assisting in enabling a systematic analysis of rehabilitation interventions (Geyh et al., 2004).



The objectives of the study can be conceptualized within the framework of the ICF as the loss of ability to perform functional activities (activity limitations) and the inability to resume life roles (participation restrictions), can be identified within the framework. To identify which self-management strategies were employed to address the activity limitations and participation restrictions that lies within the conceptual framework of the ICF, Bandura's social cognitive theory (1989), will be utilized as the theoretical framework for this study to support the conceptual framework. Bandura's social cognitive theory will be presented in further detail in Chapter 2.

#### **1.4.1 Activity Limitations Post Stroke**

According to the ICF classification, activity is described as an individual's execution of a task, whereas participation is an individual's involvement in a life situation. Described within



the ICF framework Activities of Daily Living (ADLs) refer to mobility, self-care and domestic life. Domestic life activities include: buying goods, utilizing services, preparing meals and performing basic household tasks (like cleaning). Care activities include: bathing, toileting, and dressing, eating, drinking and looking after one's health (WHO, 2001). Mobility activities refer to lifting and carrying objects, using public or private transportation and driving, and walking and moving around using equipment (WHO, 2001). More than 80% of participants with mild stroke can achieve maximum improvement in ADL function within three weeks (Langhorne, Coupar, & Pollock, 2009). However, some stroke survivors experience limitations in physical functioning, instrumental ADLs and participation (Veerbeek, Kwakkel, Wegen, Ket, & Heyman, 2011).

Difficulty in walking is a common problem in neurological diseases, such as strokes, and walking is the activity of daily living on which participants place the greatest value (Pearson, Busse, van Deursen, & Wiles, 2004) as walking in itself is something so basic and fundamental. The loss of mobility is most frequently mentioned by stroke survivors. Often, they require the use of mobility devices, such as canes, walkers or wheelchairs (Mumman, 2000). Mobility impairment and decreased endurance, stamina and balance lead to the need for a wheelchair. Wheelchairs, as a mobility device, acts as a facilitator for community participation and community integration (Barker, Reid, & Cott, 2006).

Hammel, Jones, Gossett and Morgan (2006) stated that individual barriers post stroke fall into four main areas, namely: physical, social, cognitive and psychological. Physical and cognitive problems are the most frequently identified and the most important reason for nonparticipation (Hammel et al., 2006). Subjects in the study undertaken by these authors frequently reported cases of distraction or inattention, which caused them to become

disorientated or lost, which was heightened in crowded areas with high noise levels, or in places with significant multisensory stimulation (Hammel et al., 2006).

Activity limitations lead to dependency issues in stroke survivors. They therefore require care or assistance from others. Mobility impairment and decreased endurance, stamina and balance lead to the need for a wheelchair. This mobility device acts as a facilitator for community participation and community integration (Barker, Reid, & Cott, 2006).

#### **1.4.2 Participation Restrictions Post Stroke**

Following a stroke, the attainment of independent community ambulation is a challenging rehabilitation goal (Lord, McPhearson, McNaughton, Rochester, & Weatherall, 2008). Inadequate ambulatory ability in stroke participants directly affects their ability to participate in the community (Taylor, Stretton, Mudge, & Garret, 2006). A study of barriers for community living and the participation of stroke survivors in America, established that stroke participants found it difficult to ask for help from others. When asking for help from others, many of the participants were given responses that the stroke survivor felt was either unhelpful, or were dismissive or disrespectful towards them; sometimes their requests for help were ignored completely (Hammel et al., 2006).

In a South African-based study, participants reported that they had problems accessing public transport, for example, to hail/flag down a taxi (Kahonde, Mlenzana, & Rhoda, 2010). The public transport challenges experienced by the participants in this study led them to hire transport from their neighbours, which was often a financial strain on them (Kahonde et al., 2010). In a study by O'Donovan et al. (2009), a high percentage of participants of all disability types experienced restrictions in socializing (39.9%) and leisure (31.6%). The

majority of participants stated that they were bothered to some extent by the restrictions they experienced, while 68.5% stated that they had been emotionally affected by their disability.

### **1.4.3 Environmental Barriers and Facilitators**

#### ***1.4.3.1 Physical Barriers***

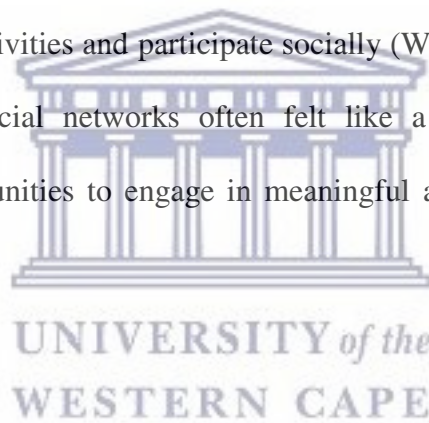
Environmental barriers are those that make participation in the community difficult. It is important to consider barriers in the environment, as they restrict social participation. A qualitative study by Rimmer, Rubin and Braddock (2000), which looked at the facilitators and barriers in partaking in a fitness regime for people with disabilities, established that they perceived their natural environment as inherently inaccessible, thus hindering participation.

Traditionally, most environmental interventions focus exclusively on architectural barriers in the individual's home, but many other physical and social factors could determine how a person carries out his/her daily activities (Rochette, Desrosiers, & Noreau, 2001).

The study by O'Donovan et al, (2009), established that the physical environment was the most common barrier to participation for people with physical disabilities (46.6%) In a study by Rimmer, Riley, Wang, Rauworth and Jurkowski (2004), participants stated that the lack of kerb ramps and too narrow doorways were features that made the environment inaccessible to them. Barker et al. (2006) found that physical environmental barriers included heavy doors, constricted store aisles, crowded places, stairs, uneven or bumpy sidewalks, rough ground, such as potholes and grass, inaccessible washrooms, foul weather and negative societal response. Many stroke participants could walk around with a quadripod in their homes, but needed a wheelchair for assistance in activities in the community, for fear of falls due to uneven surfaces or to cope in crowded or hurried situations (Barker et al., 2006).

### ***1.4.3.2 Social Environmental Barriers***

Social environmental barriers include obstacles in fundamentals such as social support from family members and the utilization of health and social services (Vincent et al., 2007). According to Chau, Woo and Chang (2007), social support for stroke participants, whether emotional, informational, and instrumental or appraisal, has a positive influence on their functional and psychosocial recovery. Poor social support is believed to be influenced by the functional and cognitive state of the individual stroke survivor (Mackenzie & Chang, 2002). Participants in a study by Wood, Connelly and Maly (2010), felt that their independence was compromised when they required help from others; not that learning to accept help had enabled them to engage in activities and participate socially (Wood, Connelly & Maly 2010). Participants with smaller social networks often felt like a burden to others, had low motivation and fewer opportunities to engage in meaningful activities (Wood, Connelly & Maly, 2010).



### ***1.4.3.3 Attitudes of others as an environmental barrier or facilitator***

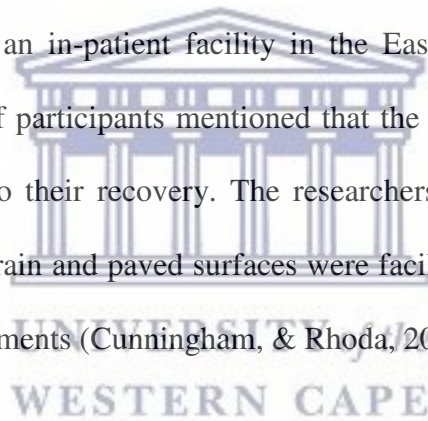
Many stroke patients felt that the negative attitudes of medical and health care professionals with whom they came into contact, had affected their rehabilitation and wellbeing negatively (Lock, Jordan, Bryan, & Maxim 2005). Participants in a study by Hammel, Jones, Gossett, & Morgan, (2006) had experienced dismissive or distressful treatment from certain members of the community when they asked for help. Some participants stated that at times their requests had been completely ignored (Hammel, Jones, Gossett, & Morgan, 2006). In contrast to this, Alguren, Lundgren-Nilsson, & Sunnerhagen (2009), found that the participants in their study

described family members, friends and health care professionals' attitudes to them as supportive and facilitatory.

In a South African-based study, the participants experienced the attitudes of service providers as respectful; communication was good and the service providers supported them emotionally (Kahonde, et al., 2010).

#### ***1.4.3.4 Environmental Facilitators***

In a study by Cunningham, & Rhoda (2014), which looked at the outcomes of stroke participants discharged from an in-patient facility in the Eastern Cape, South Africa, the researchers found that 86% of participants mentioned that the use of a mobility device post stroke acted as a facilitator to their recovery. The researchers also found that participants mentioned that ramps, flat terrain and paved surfaces were facilitators within the participants home and community environments (Cunningham, & Rhoda, 2014)



## **1.5 RESEARCH QUESTION**

What are the self-management strategies employed by stroke survivors in the Western Cape, SA to facilitate functioning?

## **1.6 AIM**

The study aimed to explore the self-management strategies employed to facilitate functioning by stroke survivors living in the Western Cape, South Africa.

## 1.7 OBJECTIVES

- 1.7.1** To explore the self-management strategies employed by stroke survivors in the Western Cape to address activity limitations.
- 1.7.2** To explore the self-management strategies used by stroke survivors in the Western Cape to address participation restrictions.

## 1.8 DEFINITION OF TERMS

**Activities of daily living (ADLs)** is a term used in health care to refer to daily self-care activities within an individual's dwelling, in outdoor environments, or both. Health professionals routinely refer to the ability or inability to perform ADLs as a measurement of the functioning of an individual, particularly with regards to persons with disabilities and the elderly are usually noted with, things we normally do, for example: feeding ourselves, bathing, dressing, grooming, work, homemaking, and leisure. (Krapp, 2006).

**Activity limitations** are difficulties an individual experiences in executing activities (WHO, 2001).

**Challenge** is something needing excessive mental or physical effort in order to be done successfully and which therefore tests an individual's ability (Cambridge Advanced Learner's Dictionary, 2008)

**Disability** is an umbrella term for impairment, activity limitation and participation restriction. It denotes the complex interaction between an individual's health condition and contextual factors, which are environmental and personal factors (WHO, 2001).

**Environmental barriers** refer to environmental factors that hinder the performance of participation in life activities (Doyle & O'Donovan, 2008).

**Environmental factors** constitute the person's life milieu that can influence the accomplishment of daily activities or social roles (Rochette, Desrosiers, & Noreau, 2001).

**Impairment** is the loss and/or abnormality of mental, emotional, physiological or anatomical structure or function; this term includes all losses or abnormalities, not just those attributable to the initial patho-physiology and it also includes pain as a limiting experience (WHO, 2001).

**International Classification of Functions, Disability and Health (ICF)** – ICF belongs to the “family” of international classifications developed by the WHO for application to various aspects of health. The WHO family of international classifications provides a framework to code a wide range of information about health (e.g. diagnosis, functioning and disability, reasons for contact with health services) and uses a standardized common language permitting communication about health and health care across the world in various disciplines and sciences (WHO, 2001).

**Participation Restriction** is defined as "problems an individual may experience in involvement in life situations" and refers to the personal and societal consequences of health conditions (WHO, 2001, p. 212-213).



**Stroke**, as defined by the WHO, is a clinical syndrome characterized by rapidly developing clinical symptoms and/or signs of focal, and at times global (which applied to participants in deep coma and those with subarachnoid haemorrhage) loss of cerebral function, with symptoms lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin (WHO MONICA Project, 1988). This definition excludes transient ischemic attacks (TIA) (which last for less than 24 hours), subdural or extradural haemorrhage, and infarction or haemorrhage secondary to infection or malignancy (Intercollegiate Stroke Working Party, 2012).

## 1.9 OUTLINE OF THE CHAPTERS OF THE THESIS

This thesis is organized into six chapters:

**Chapter one** includes the background of study. The background of the study introduces pertinent concepts that encapsulate the broad aim of the study. It focusses on stroke, limitations encountered in daily life, the conceptual framework for the study (ICF) and various limitations to participation restrictions within the society. In addition, the statement of the problem, aims and objectives and significance of the study are included. The definition of terms and full meaning of acronyms is included in this chapter as well.

**Chapter two** presents a review of relevant literature in order to understand the need for the study. It will also further explore the theoretical framework (Banduras social cognitive theory) for the study. The concept of self-management will be introduced as well as the role it plays in rehabilitation. The most common self-management strategies in literature will also be highlighted.

**Chapter three** presents the methodology employed to answer the study objectives. Chapter three presents the overview and rationale of the methodology used in this study. The research



settings, research design, population and sampling, data collection methods, research instruments, Braun and Clarke's thematic analysis and ethical consideration are described in this chapter.

**Chapter four** contains the result of the thematic analysis of the qualitative data that seeks to answer the objectives of the study.

**Chapter five** discusses the results of this qualitative study with reference to published literature. Limitations of the study are also presented.

**Chapter six** summarizes the study and draws conclusions from the results. Recommendations for stakeholders for future research are made based on the study findings, as well as needs that emerged from the review of the literature.

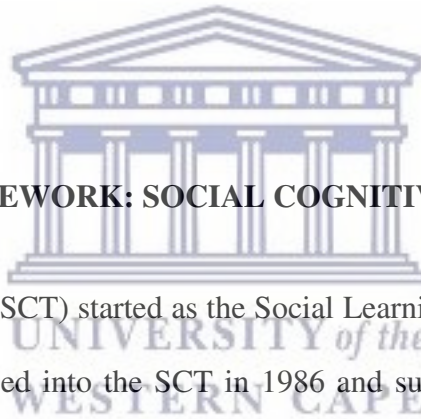


## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

This literature review chapter will illustrate the current knowledge relevant to the present study. This chapter is organized into five major sections. The first section concentrates on the theoretical framework (Bandura's social cognitive theory). The literature review also focusses on the concept of self-management, what the main benefits of self-management programmes and self-management support. This chapter concludes with the most common self-management strategies identified in literature.



#### **2.2 THEORETICAL FRAMEWORK: SOCIAL COGNITIVE THEORY**

The Social Cognitive Theory (SCT) started as the Social Learning Theory (SLT) in the 1960s by Albert Bandura. It developed into the SCT in 1986 and suggests that learning occurs in a social context with a dynamic and reciprocal interaction of the person, environment, and behaviour.

SCT considers the unique way in which individuals acquire and maintain behaviour, while also considering the social context in which individuals perform the behaviour. The theory takes into account an individual's past experiences, which factor into whether behavioural action will occur. These past experiences influences reinforcements, expectations, and expectancies, all of which shape whether a person will engage in a specific behaviour and the reasons why a person engages in that behaviour. The first five constructs were developed as

part of the SLT; the construct of self-efficacy was added when the theory evolved into SCT (Bandura, 1989, 2001).

The six constructs are as follows:

1. Reciprocal Determinism – The central concept of SCT. This refers to the dynamic and reciprocal interaction of an individual (individual with a set of learned experiences), environment (external social context), and behaviour (responses to stimuli to achieve goals).
2. Behavioural Capability - This refers to an individual's actual ability to perform a behaviour through essential knowledge and skills. In order to successfully perform a behaviour, a person must know what to do and how to do it.
3. Observational Learning - This asserts that people can witness and observe a behaviour conducted by others, and then reproduce those actions.
4. Reinforcements - This refers to the internal or external responses to an individual's behaviour that affect the likelihood of continuing or discontinuing the behaviour. Reinforcements can be self-initiated or in the environment, and reinforcements can be positive or negative. This construct of SCT most closely ties to the reciprocal relationship between behaviour and environment.
5. Expectations - This refers to the anticipated consequences of an individual's behaviour. Outcome expectations can be health-related or not health-related. People anticipate the consequences of their actions before engaging in the behaviour, and these anticipated consequences can influence successful completion of the behaviour.
6. Self-efficacy - This refers to the level of a person's confidence in his or her ability to successfully perform a behaviour. Self-efficacy is influenced by an individual's

specific capabilities and other individual factors, as well as by both the environmental barriers and facilitators (Bandura, 1989, 2001).

Most self-management programmes are based on Banduras (1989; 1997) social cognitive theory, in which an individual's belief in their own capability to produce a change in a specific behaviour (self-efficacy) is said to be critical to their success. This belief in one's own capabilities is defined as self-efficacy.

There are four main sources of self-efficacy: mastery experiences, vicarious experiences, verbal persuasion and physiological feedback (Bandura, 1997). Mastery experiences include positive experiences in a task or skill. For people with a stroke, confidence could be multiplied following accomplishment of a small personal goal through independent effort (Jones, Mandy, & Partridge, 2007). Vicarious experience is gained through the comparison and modelling of others, as it can be beneficial to observe someone perceived to be similar (model) successfully performing a task, e.g. learning from other people's experiences of the recovery period post-stroke. (Bandura, 1997; Johnston et al., 2007; Jones, Mandy, & Partridge, 2007; Kendall, Catalano, Kuipers, Posner, Buys, & Charker, 2007; Schwartzer, 1992; Shapero, Meisler, & Silver, 2000; van de Laar & van der Bijl, 2001; Watkins et al., 2007).

Verbal persuasion through the use of coaxing and verification from a significant other health care professional, important family member or skilled stroke survivor) serves to increase an individual's belief about their personal level of skill (Bandura, 1997). Physiological feedback is where efficacy beliefs are formed from feedback produced by an individual's own physiological state. Self-efficacy may be increased by the interpretation of individual's

physical and emotional feelings as positive, rather than negative, e.g. unaided walking post stroke without feeling unsteady (Bandura, 1997; Ewart, 1992; Johnston et al., 2007; Jones, Mandy, & Partridge, 2007; Kendall et al., 2007; Schwartz, 1992; Shaper, Meisler, & Silver, 2000; Watkins et al., 2007).

There is an increasing platform of evidence suggesting that self-efficacy plays a significant role in the improvement of management of long-term conditions, including stroke (Jones, 2006; Korpershoek, van der Bijl & Hafsteinsdóttir, 2011; Marks, Allegrante, & Lorig 2005; Resnick 2002). Self-efficacy is also said to determine whether an individual will, at first, attempt an action and also whether they will persevere in overcoming obstacles, and has been suggested to be a useful predictor of disablement post stroke (LeBrasseur, Sayers, Oullette, & Fielding, 2006). There is also a relationship between self-efficacy, quality of life and depression post stroke (Robinson-Smith, Johnston, & Allen, 2000) where participants with higher self-efficacy tend to have greater functional independence and a reduced incidence of falls (Hellstrom, Lindmark, Wahlberg & Fugl-Meyer, 2003). Self-efficacy beliefs can determine how people feel, think, motivate themselves and behave with regards to their health (Jones & Riazi, 2011). Thus, self-efficacy influences motivation positively which in turn influences health behaviours by shaping the goals people set, how much effort they invest in achieving those goals and their resilience when faced with difficulties, challenges or failure (Dixon, Thornton, & Yound, 2007).

For this work, the social cognitive theory relates to self-efficacy as it forms the basis of self-management programmes. Self-management relates to one's ability to manage one's consequences post stroke and self-efficacy has been proven to be pivotal in the management and improvement of long-term conditions. Therefore, the work that Bandura did was

fundamental, as self-efficacy has shown to build resilience in participants in better managing their chronic conditions (Dixon, Thornton, & Yound, 2007).

## **2.3 SELF-MANAGEMENT**

### **2.3.1 The Concept of Self-Management**

Long-term conditions, such as stroke, cardiovascular disease and diabetes, are a common and emergent problem in many countries (Singh, 2016), with considerable impact on the psychological and physical health of people with long-term conditions as well as the services that support them (Mackay & Mensah, 2004). One of the first uses of the term self-management appeared in a book on the rehabilitation of chronically ill children written by Thomas Creer (2000). Since the mid-1960s, Creer and his colleagues at the Children's Asthma Research Institute and Hospital have been using the term in conjunction with their paediatric asthma programme in which they acknowledge the early writings of Albert Bandura (1989). Creer and his colleagues felt that the term self-management referred to the patient as an active participant in their treatment or management. Self-management activities may be carried out by participants, independently, with support from peers (or peer relationships) and/or occur within broader support networks (Loeb, Eide, Jelsma, Toni, & Maart, 2008) and may involve aid from practitioners (Barlow et al., 2002). The assistance from practitioners or health care professionals in the context of self-management is known as self-management support. Self-management support is the care and encouragement provided to people with chronic conditions and their families, to assist them in understanding their central role in managing their illness, make informed decisions about care, and engage in healthy behaviours (Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011).

### 2.3.2 Why the Need for Self-Management Programmes?

Reviews of the long-term concerns relating to living with stroke reveal a complexity of problems faced by individuals; including social isolation, lack of specialist support, reduction in mobility and life roles (Hackett, Chaturangi, Varsha, & Anderson, 2005; McKeivitt, Redfern, Mold, & Wolfe, 2004). Stroke victims often still struggle once discharged from an acute setting and their support systems (family and carers) are often ill equipped for handling the responsibilities of home care (Ostwald, Davis, Hersh, Kelley, & Godwin 2008) and their relationships are often strained (Gillespie & Campbell, 2011). The onset of a stroke results in enduring changes in the lives of caregivers of people who have had a stroke as well as their respective families (King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002), one of the reasons for these enduring changes as noted by Bakas & Burgener (2002), could be that the dynamics within the caregiving process are complex and multivariate.

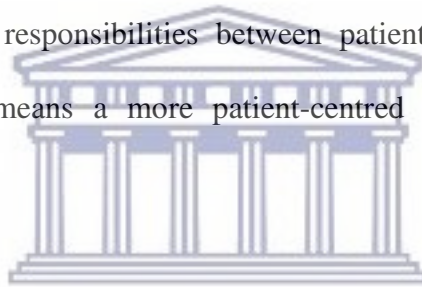
In contrast to research supporting individuals with other long-term conditions (Werfalli et al, 2015; Turner, Anderson, Wallace & Bourne, 2015), there has been minimal research on such programmes to assist individuals in the longer-term post stroke. One reason for this could be the limited understanding of the unique challenges which emerges throughout the trajectory of living with a stroke (Jones, & Brimicombe, 2014). By understanding these challenges, targeted self-management programmes could be used to aid recovery in a sequential manner. As a self-management programme is only fully effective when it takes into consideration the uniqueness of each stroke survivor and their individual challenges. (Vassilev, et al, 2011).



## 2.4 KNOWN BENEFITS OF SELF-MANAGEMENT PROGRAMMES

To facilitate the development of resources to enable self-efficacy and self-management for stroke survivors in the community, a comprehensive understanding of the role of self-efficacy and self-management in improving health outcomes of participants living with stroke in the community is required.

On an individual level, a patient's self-management has proven to have positive effects on health outcomes such as quality of life, compliance and lifestyle (Barlow et al, 2002; Ditewig, Blok, Havers, & van Veenendaal, 2010; Gordon & Galloway, 2007; Zwerink et al., 2014). Furthermore, sharing responsibilities between patient and provider may improve patient involvement which means a more patient-centred organization for health care delivery.



Regarding the future rehabilitation of stroke survivors, many studies (Gibson et al., 2000; Jovicic, 2006; Zwerink et al., 2014), have found that self-management lessens use of the health care system and reduces cost. The use of self-management also helps participants manage their health more effectively (Boger, Demain, & Latter, 2012). Therefore, exploring stroke survivors' experiences and contextualizing the challenges they face is important to understanding the challenges faced by stroke survivors and what is helpful in coping with these challenges. It is critical to developing interventions that best support them throughout recovery and in the longer term, post their stroke recovery (Ch'ng, French, & Mclean, 2008; Wood, Connelly & Maly).



Self-efficacy programmes aid people with chronic disability to manage their life roles and improve psychosocial outcomes (Marks, Allegrante, & Lorig 2005; McKenna, Jones, Glenfield, & Lennon, 2015). For people living with stroke, self-efficacy is positively associated with mobility, ADLs, and quality of life; and negatively associated with depression (Robinson-Smith, Johnston, & Allen, 2000). To develop a novel intervention to provide information for stroke survivors, it is essential to bear in mind that knowledge alone is not sufficient to ensure the maintenance or even the improvement in the level of functioning achieved during rehabilitation.

Personal-psychological variables, especially self-efficacy which forms the basis of self-management programmes, play a key role on how and to what extent information provided is implemented (Barlow et al., 2002; Jones & Riazi, 2011; Lorig & Holman, 2003). The enhancement of self-efficacy has been associated with the improvement in patient self-management, and has frequently been used in patient education programmes to improve participants' self-management skills (Battersby et al., 2010; Jones, 2006).

## **2.5 THE ROLE OF REHABILITATION TO INDUCE SELF-EFFICACY AND INDEPENDENCE**

Self-management involves the patient with a long-term condition working to manage their condition in collaboration with a complex health- and social-care network (Creer & Holroyd, 2006). Self-management programmes are concerned with coping with or controlling the nature and impact of illness or long-term conditions and it is common for people with injuries

or long-term conditions to be prescribed physiotherapy as part of their rehabilitation (Spetch & Kolt, 2001).

### **2.5.1 Rehabilitation and the social cognitive theory**

Two social-cognitive variables that have been identified are self-efficacy and observational learning (Wesch et al., 2012). Self-efficacy reflects an individual's belief in his or her ability to engage in specific behaviours that will yield a favourable outcome (Bandura, 1986). It narrates to one's sense of competency and proficiency, and therefore affects one's choice of behaviour, activity, and exerted effort (Bandura, 1977).

The exercise psychology literature has fixated on three different types of self-efficacy: task, barrier, and scheduling (DuCharme & Brawley, 1995; McAuley, 1992; Rodgers, Hall, R., Blanchard, McAuley, & Munroe, 2002). Task efficacy is described as the confidence in one's ability to perform the fundamental aspects of a task in a specific situational context. Barrier efficacy is defined as confidence in one's ability to perform a task under challenging conditions or to overcome social, personal and environmental constraints, and scheduling efficacy is the confidence in one's ability to schedule or plan strategies for carrying out a specific action. As both barrier and scheduling efficacy are self-regulatory in nature (Bandura, 1997), the two have been grouped together and considered as coping efficacy, which refers to an individual's confidence in the ability to perform tasks under challenging conditions (Maddux, 1995).

Observational learning or imagery has been defined as “an experience that mimics real experience. We can be aware of ‘seeing’ an image, feeling movements as an image, or

experiencing an image of smell, tastes, or sounds without actually experiencing the real thing” (White & Hardy, 1998). Cognitive imagery is used to rehearse rehabilitation exercises, whereas motivational imagery is used to set goals, control arousal levels, and improve self-confidence. Healing imagery entails imagining the physiological processes occurring during rehabilitation (e.g., tissue and/or bone healing). Increased imagery use during rehabilitation has been found to be related to increased rehabilitation adherence and faster recovery (Cupal & Brewer, 2001; Driediger, Hall, & Callow, 2006).

Self-efficacy and imagery are two social-cognitive variables that may positively influence adherence in an injury rehabilitation setting, which may subsequently improve treatment outcome. (Wesch et al., 2012).



### **2.5.2 Self-management support**

In the medical sector, health care professionals often dictate the patients’ outcomes by taking the lead. Self-management aims to shift this focus onto shared decision making which enables the health care professional and patient to co-create specific outcomes for the patient (Jones, & Brimicombe, 2014). As the long term impact of stroke requires much attention (De Wit, et al, 2017), it is necessary that stroke survivors are taught to self-manage post stroke. Thus, health-care professionals need to focus on supporting stroke survivors once rehabilitation has ceased to allow for the successful adjusting to life post stroke through self-management (Jones, & Brimicombe, 2014)

Self-management support is the care and encouragement provided to people with chronic conditions and their families, to assist them in understanding their central role in managing

their illness, make informed decisions about care, and engage in healthy behaviours (Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011). Therefore, the role of the rehabilitation professionals in self-management is to serve as a base of support and guide for the participants who make use of self-management strategies and/or programmes.

## **2.6 COMMON SELF-MANAGEMENT STRATEGIES**

Self-management, based on social cognitive theory, is a health behaviour change strategy emphasizing the expectations a person has about being able to achieve a specific behaviour (Bandura, 1989; 1997). These expectations predict the degree of success a person will have in initiating a new behaviour, (Bandura, 1977). The Stanford Patient Education Research Centre's Chronic Disease Self-Management Program (CDSMP) is one self-management model that has been successful in improving health behaviours among persons with chronic conditions (Bodenheimer, Lorig, Holman, & Grumbach 2002; Chodosh et al., 2005; Lorig & Holman, 2003; Warsi, Wang, LaValley, Avorn, & Solomon, 2004) as well as reducing outpatient and inpatient service needs (Lorig & Holman, 2003; Ory et al., 2013). This model emphasizes improving confidence and success by using self-directed action planning, problem-solving, and social support (Lorig & Holman, 2003). Self-management programmes (SSMPs) for stroke is rare and is not well documented (Lennon, McKenna, & Jones, 2013) therefore, the focus will firstly be on self-management strategies found in different conditions in the field of physiotherapy before current SSMPs for stroke will be highlighted.

### **2.6.1 Self-management in physiotherapy**

The most common self-management strategies recommended for the treatment of rheumatoid arthritis (RA) includes: exercise of the hands and joints, rest, heat, wrist working splints, joint

protection, relaxation and using technical aids (Hammond, 2004). A study by Katz (2005), which examined the self-management behaviour that RA participants used to cope with five RA-related stressors, (namely: pain, fatigue, physical limitations, joint changes and symptom unpredictability), found that self-management behaviours varied and that such behaviours included taking medications, using heat or exercising, rest and talking with friends or family for advice or support (Coulton et al., 1990; Cronan, Kaplan, Posner, Blumberg, & Kozi, 1989; Davis, Cortez, & Rubin, 1990; Hampson et al., 1993; Verbrugge & Ascione, 1987).


Coping has been defined as “cognitive and behavioural efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the individual” (Folkman & Lazarus, 1988). Blalock, de Vellis, Holt and Hahn. (1993), identified a number of behavioural coping strategies for difficulties with daily and leisure activities, work, and social relationships that might be construed as self-management behaviours, including modification, perseverance (attempting to continue despite problems or challenges), and material resources (using special equipment or devices).

In a study by Simon et al., (2016), a total of 51 were interviewed to explore their self-management strategies for episodic breathlessness in advanced diseases. Six main themes emerged from the qualitative interviews. The six themes included: 1) reduction of physical activity; 2) cognitive and psychological strategies; 3) breathing techniques and positions; 4) air and oxygen; 5) drugs and medical devices, and 6) environmental and other strategies.

Studies relating to physiotherapy with regards to the following conditions: urinary incontinence, ankle sprains, upper and lower limb injuries, sport-related injuries, (chronic and acute) lower back pain, haemophilia, total hip and knee replacements, hip and knee

osteoarthritis and chronic lung disease have solely focussed on exercise as a self-management strategy. (Beattie, Silfies, & Jordon, 2016; Peek, Sanson-Fisher, Macklenzie, & Carey, 2016; Zwerink, et al, 2014).

In a systematic review of stroke literature, Parke et al., (2015) found little evidence specifically using the terminology 'self-management'. The researchers did, however, discover core elements of self-management support including problem solving, decision making, and goal setting that were delivered to stroke survivors and their caregivers within the context of therapy rehabilitation.

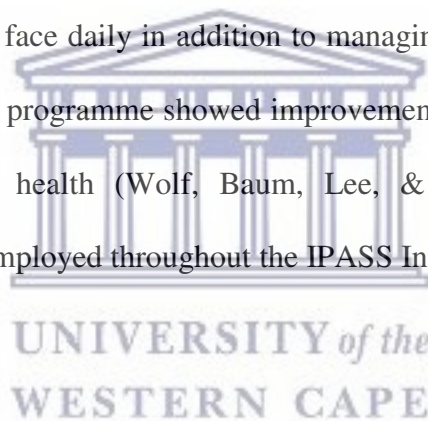


There is two programme that uses the term, self-management, specifically, 1) the Bridges SSMP and 2) the Development of the Improving Participation after Stroke Self-Management Program (IPASS) namely. The Bridges SSMP is an individualized, theory-driven programme based on self-efficacy principles which comprises structured one-to-one sessions with a professional to support participants in setting goals, recording progress and planning activities; it incorporates a patient held workbook to facilitate a personal record of goals, progress and helpful strategies (Jones, Mandy, & Partridge, 2009). The self-management strategy that is employed throughout the Bridges SSMP is self-efficacy.

A study by Jones, McKevitt, Riazi and Liston, (2017) aimed to show the extent to which experiences from community-dwelling stroke survivors receiving rehabilitation in control (usual care) and intervention (Bridges SSMP) sites reflected the differences in rehabilitation received and whether their understandings aligned with the self-management approach employed. The researchers concluded that therapy focused on supporting self-efficacy and

self-management could be reflected in experiences of stroke survivors (Jones, McKeivitt, Riazi, & Liston, 2017).

The IPASS Intervention (Wolf, Baum, Lee, & Hammel, 2016) involves a participatory, small group, problem-solving process that is based upon the self-management and environmental management intervention of Lorig and Holman (2003). IPASS adhered to all concepts and contents of the chronic disease self-management program (CDSMP) as well as seven additional sessions with emphasis on home, community, and work management post stroke were supplemented to the original CDSMP (Lorig, Ritter, Laurent & Plant, 2006), in order to develop a programme to improve participation post stroke. The results from the IPASS study showed that persons with chronic stroke can partake in a self-management programme that addresses the difficulties they face daily in addition to managing their health and symptoms. The participants in the IPASS programme showed improvement in self-efficacy in managing their participation and their health (Wolf, Baum, Lee, & Hammel, 2016). The self-management strategy that is employed throughout the IPASS Intervention is self-efficacy.



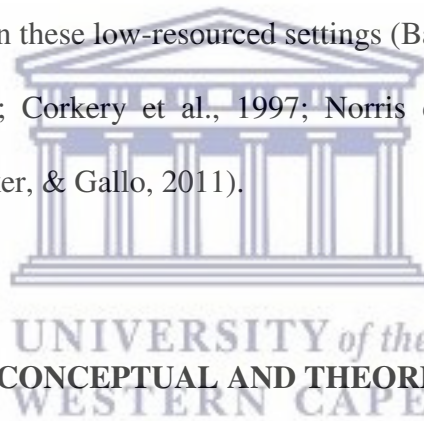
### **2.6.3 Self-management in the context of a developing country**

According to the World Economic Situation and Prospects (WESP) (UN, 2014) SA is categorized as a developing country. There is a need to find out which self-management strategies are employed in developing countries for further research to develop a context fitting for SA (which is the aim of this study). The most common condition highlighted in developing countries with regards to self-management is, diabetes. This could be due to diabetes being one of the largest global health emergencies of the 21st century. Recent estimates indicate that 415 million adults have diabetes and by 2040 this figure will rise to 642 million (IDF Diabetes Atlas, 2015). In a systematic review by Dube, van den Broucke,



Housiaux, Dhoore, and Rendall-Mkosi (2015), the researchers found that there were shortcomings to diabetic self-management programmes.

Of the studies reviewed, most interventions were found to be provided by a host of health professionals. While this suggest progress in the provision of diabetic self-management programmes it is clear that developing countries are not equipped with this method of implementation due to the shortage of health care professionals, particularly in rural areas (WHO, 2010). This is especially relevant to the context of SA, due to the limited health resources in SA (Stanmore & Waterman, 2007). A strategy that has proven to be effective is that peer and community health care workers can be trained to administer such self-management interventions and professional health care staff can be widely used in a supervisory and training role in these low-resourced settings (Balagopal, Kamalamma, Patel, & Misra, 2012; Clark, 2008; Corkery et al., 1997; Norris et al., 2006; Philis-Tsimikas, Fortmann, Lleva-Ocana, Walker, & Gallo, 2011).



## **2.7 ALIGNMENT OF THE CONCEPTUAL AND THEORETICAL FRAMEWORK**

The conceptual framework of the ICF (WHO, 2011) takes into consideration the individual, their disease, the inter and intra workings of their personal and environmental facilitators and barriers. In a similar manner Banduras (1986) SCT takes into consideration and suggests that learning occurs in a social context with a dynamic and reciprocal interaction of the person, environment, and their behaviour.



This demonstrates the alignment of the conceptual and theoretical framework, in that an individual in essence is not singular but that rather their environment need to be taken into consideration when dealing with the complex nature of an individual's life.

## **2.8 SUMMARY OF THE CHAPTER**

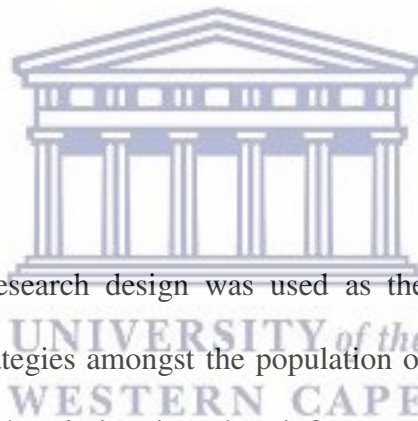
Bandura's social cognitive theory is an individual's belief in their own capabilities and the majority of SSMPs are based on this theory. A collective term for an individual's belief in their own capabilities is: self-efficacy. Self-efficacy plays a significant role in the improvement of long-term conditions and has been found to produce greater functional independence. The Bridges SSMP is an individualized programme based on self-efficacy which supports stroke survivors in setting goals and recording progress, through a patient-held workbook which consists of helpful strategies employed by stroke survivors to assist recovery. Stroke survivors often still have challenges once discharged from an acute setting. There is a need for SSMP to address the long-term recovery of their condition as well as the strategies to implement self-management programmes in a developing country.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 INTRODUCTION**

In this chapter, a description of the study setting is provided. The researcher also presents the methods used in the study. The study design, study population, sampling method and instrumentation are described. The procedure of data collection and how data analysis was carried out is explained. The methodology chapter concludes with ethical considerations pertaining to the study.



#### **3.2 RESEARCH DESIGN**

An exploratory, qualitative research design was used as the overarching methodology to describe self-management strategies amongst the population of stroke survivors in the South African context. Qualitative description is a low-inference method that is well suited to gathering facts about the experiences of people living in their natural setting, which is necessary for providing a comprehensive description of a particular phenomenon (Sandelowski, 2000). The researcher remained close to the data to ensure that the findings are grounded within the descriptions provided by the participants (Sandelowski, 2010; Strauss & Corbin, 1998). This was fitting to the study as the experiences of stroke survivors endeavoured to be explored in a meaningful way.

### 3.3 RESEARCH SETTING

The research project was conducted in an urban (Mitchells Plain) and a rural (Genadendal) area of the Western Cape, SA. The areas were conveniently selected based on the fact that they were accessible to the researcher. There is great disparity between the health care services in these two areas (Rural Health Advocacy Project (RHAP), 2015). The association between poverty, poor health and health care outcomes has been well established; not only do poor people experience higher burdens of disease because of various social determinants, they also have less access to care (Peters et al., 2008). Globally research continues to show that this is particularly acute for rural populations, which tend to carry a disproportionate burden of both communicable and non-communicable diseases and across almost all indicators experience worse health outcomes (Smith, Humphreys, & Wilson, 2008). The South African context is no different (RHAP, 2015).

#### Health Care Services

The urban sample which was targeted is a community in the Cape Metropole district, namely Mitchells Plain, Cape Town, SA. According to the City of Cape Town (2013) Mitchells Plain has a total population of 310 485, with 67 995 households. Ninety-five percent of the houses in this community are formal dwellings and 76% of the total labour force in the community is employed. The total number of people living with disabilities in Mitchells Plain is 9285. The three main causes of disability in Mitchells Plain are as follows: physical disability (most common), affecting 32.6% of the disabled population, emotional disability (18.2%) and visual disability (16.6%) respectively (City of Cape Town, 2005). Various levels of rehabilitation are offered in the Cape Metropole area. At a tertiary level there is the Mitchells Plain District Hospital (MPDH), which is aimed at providing individuals with Intensive Care Unit (ICU)/high-care and acute stage management of conditions. Then there is primary (step-

down) level rehabilitation, such as Life Esidimeni Intermediate Care (LEIC), aimed at low intensity rehabilitation for acute and sub-acute patients. Finally, there is a secondary level rehabilitation, such as the Western Cape Rehabilitation Centre (WCRC), aimed at individuals with a more permanent type of disability needing high intensity rehabilitation. Within the community-based services in Mitchells Plain, rehabilitation is offered through the outpatient department at the community health care centre (MPCHC), and through home-based care (HBC), personnel and rehabilitation care workers (RCWs) (Western Cape Department of Health, 2007).

The rural sample which was targeted comprises the community of Genadendal in the Theewaterskloof district of the Western Cape. According to the City of Cape Town (2013) and the latest available information on the Genadendal community through the Census 2011 statistics, the total population was 5663, with 1593 households (Statistics SA, 2013). There is no information available from statistics SA on the disabled population of Genadendal. The health services provided in Genadendal are limited. There is one satellite clinic run once weekly by a Professional Nurse and a Doctor who visits this community occasionally (Appolis, J, Personal Communication, April 2016). A physiotherapist based at Caledon Hospital (34 kilometres [km] from Genadendal), (SA Explorer, 2016) services nine areas, of which Genadendal is one. Cases that cannot be handled by the professional nurse are transferred to Caledon Hospital. More serious cases are transferred to Worcester Hospital (95 km from Genadendal) or Tygerberg Hospital (122 km from Genadendal), (SA Explorer, 2016) respectively, (Appolis, J, Personal Communication, April 2016).

### **3.4 SAMPLING**

Purposeful sampling, which a technique widely used in qualitative research for the

identification and selection of information-rich cases for the most effective use of limited resources (Patton, 2002). This involves identifying and selecting individuals or groups of individuals who are especially knowledgeable about or experienced with a phenomenon of interest (Creswell & Clark, 2011).

Variation was sought in terms of the following characteristics for purposeful selection: age, gender, severity, urban versus rural and chronicity of stroke. Therefore, participants were purposively selected from those who are younger than 65 years and older than 65 years, in addition males and females were selected as well as stroke survivors who can walk independently as well as those who require assistance with walking.

An in-depth interview (Appendix E) was conducted with 14 stroke survivors in the Western Cape.

### **3.4.1 Recruitment of the urban sample**

The urban patient sample was recruited through Life Esidimeni Intermediate Care (LEIC). The researcher has access to the discharged database of patients from LEIC.

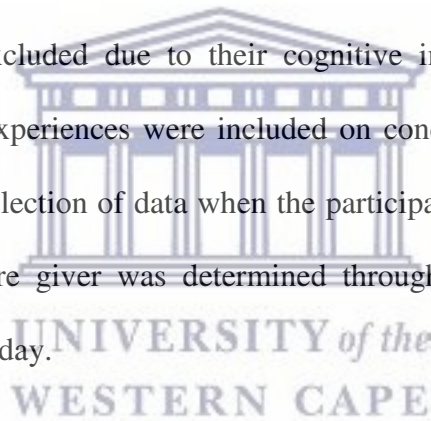
### **3.4.2 Recruitment of the rural sample**

The rural sample was a community-based sample that was recruited with the assistance of a field worker and community care workers in the Genadendal community. The researcher had access to the discharge database of patients from the Clinic in Genadendal.

In both the urban and rural sample, the researcher then separated the stroke survivors according to the inclusion and exclusion criteria, thereafter participants were selected and contacted for voluntary participation in the study.

### 3.4.3 Inclusion and Exclusion Criteria

Participants were included in the study if they had been living in the community for a minimum of six months post stroke and were able to articulate their experiences. Participants needed to be living in the community for a minimum of six months as the most functional recovery takes place six months post stroke (Langhorne, Bernhardt, & Kwakkel, 2011; Kwakkel & Kollen, 2013) the patients would therefore have experienced maximal functional recovery. Participants were excluded if they were disorientated to time and place, and thus presented with communication or cognitive problems. Participants were informally assessed for cognition impairments, thus if participants had difficulty concentrating, memory loss, problems with comprehension, problems with judgement or reasoning, and confusion (Morris, 2008) they were excluded due to their cognitive impairment. Participants who struggled to articulate their experiences were included on condition that their primary care giver could assist with the collection of data when the participants struggled to express their experiences. The primary care giver was determined through who was present with the participant for majority of the day.



After gaining ethical clearance (Appendix B) and the necessary permissions, stroke survivors were recruited through LEIC (Appendix F), a field worker, and community based carers who reside and work in Genadendal for the urban and rural area respectively by means of purposeful sampling.

### **3.4.4 Saturation**

Saturation refers to the point that sufficient data has been obtained to account for all aspects of the phenomenon have (Morse, Barrett, Mayan, Olson, & Spiers, 2002) where the collection of additional data is unlikely to provide new insight (Creswell 2007; Mason 2010).

According to Fusch and Ness, (2015) and Morse, Lowery and Steury, (2014), there are multiple factors that contribute to data saturation and that no two studies would have reached saturation at the same point in time. According to Morse, (1991, 2000) about six to 10 participants are needed in the sample before saturation is reached. In qualitative data, saturation is achieved once themes become repetitive and no new themes emerge, as evidenced by hearing the same story repetitively (Byers & France, 2008). Theoretical saturation occurs when no new themes have been identified within the data, and the researcher searches for variations of each concept contributing to the theory until redundancy occurs (Guest, Bunce, & Johnson, 2006; Miles & Huberman, 1994; Strauss & Corbin, 1990). In this study, saturation was reached prior to the inclusion of the tenth participant; it was reached at about the inclusion of the seventh participant. The other participants were interviewed since a prior appointment had been made and therefore their interviews were included in the study.

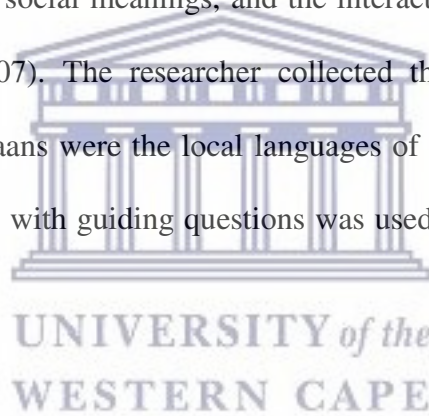
### **3.5 METHODS AND TOOLS**

An in-depth interview (Appendix E) was conducted with 14 stroke survivors in the Western Cape, (although the intended sample size was 20 stroke survivors). In-depth interviewing is defined as “conversation with a specific purpose-a conversation between researcher and informant focusing on the informant’s perspective of self, life and experience and expressed



in his or her own words” (Minchiello et al., 1995 as cited in Beale et al., 2004). The major advantage of interviews is that it gives respondents the opportunity for personal explanations and detailed responses (Skinner, 2007). According to de Vos et al. (2005), the interview is the predominant mode of data collection in qualitative research.

In qualitative research, in-depth interviewing is an egalitarian approach to interviewing which develops research relationships and rapport with participants by focusing on the participant’s experiences from their own perspective. As a qualitative method, in-depth interviewing highlights the subjective quality of different life experiences, the contextual nature of knowledge, the production of social meanings, and the interactive character of human action (Berkowitz & Marsiglio, 2007). The researcher collected the data in the patients’ local languages. English and Afrikaans were the local languages of choice by the participants. An interview guide (Appendix E) with guiding questions was used by the researcher to facilitate the interview.



The interview guide was developed based on literature (Urimubenshi, 2015; Ahuja, Clark, Morahan, Ono, Mulligan, & Hale, 2013). The following questions were posed to the participants:

### **3.6 DATA COLLECTION**

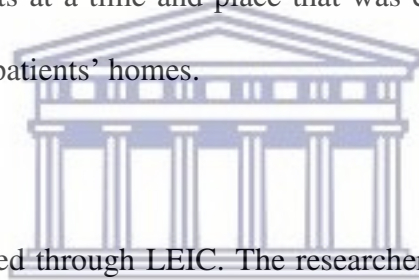
#### **Data collection procedure**

Potential participants were screened to determine if they met the inclusion and exclusion



criteria of the researcher. Recovery post stroke occurs quickly in the first 4 weeks post stroke after treatment, thereafter for the period of three to six months, recovery occurs but at a slower rate (Lee, et al, 2015). Therefore, the researcher recruited participants who were living in the community for a minimum of six months, to allow the participants to recover from their stroke.

The purpose of the study was explained to the participants facilitated by an information sheet. In addition, written, informed consent was obtained before the commencement of data collection. Data were collected through in-depth interviews. The interviews took place face-to-face with all the participants at a time and place that was convenient for the participants, which in most cases were the patients' homes.



The urban sample was accessed through LEIC. The researchers study forms part of a bigger study which is the conceptualization of the Bridges (stroke) self-management workbook. Permission was granted to Mr R. Groenewald for his study (the conceptualisation of the Bridges stroke workbook) in fulfilment for the degree Doctor of philosophy (Appendix F). LEICs hospital manager signed the permission letter. LEIC granted the researcher access to their discharged patient database. The researcher then sorted through the data to determine which discharged patients met the inclusion criteria for the study. The discharge database of LEIC consisted of 806 stroke survivors over a period of eight months. The information of the 806 patients was captured into a Microsoft excel spreadsheet (2013). From the Microsoft excel spreadsheet the researcher was able to determine the discharged patients diagnosis, age, sex, location and whether or not the discharged patients had any co-morbidities. From this the researcher was able to derive an additional Microsoft excel spreadsheet (2013) which

consisted of 86 participants who fit the inclusion and exclusion criteria of the study.

Selected participants were then contacted telephonically to set up a convenient place and time for the interview to be conducted. It was noted that some of the participants had changed their contact details or their phones were disconnected, which greatly decreased the pool of potential participants to 40. There were some potential participants who agreed to meet with the researcher but upon arrival and explanation of the study, the participants decided that they were not ready to be interviewed about their experiences.

The rural sample was accessed through a field worker who resides in Genadendal. The potential participants were identified by the field worker and home-based carers from the Genadendal Legal Information Desk. The Genadendal Legal desk is a community-based (CBO), non-government organization (NGO) and the carers from this association accompanied the researcher to the potential participants' homes. The potential participants were then screened by means of the inclusion and exclusion criteria. (Participants were included in the study if they had been living in the community for a minimum of six months post stroke and were able to articulate their experiences. Participants were excluded if they were disorientated to time and place). Participants were presented with information sheets (Appendix C) to inform them about the study with regards to its value and benefits, and clarity on the study was verbally provided to the participants. The patients were also assured of confidentiality and anonymity and they had the right to withdraw from the study at any stage. There was no obvious risk involved in participating in the study. After the participants agreed to engage in the study, signed written consent forms (Appendix D) were then presented to the participants. Signed written consent was obtained for the recording of the participants' voices from all participants or the participants' guardians/caregivers prior to the interview to affirm that they were satisfied with the process. The interviews were audio-recorded on a digital voice recorder and all 14 of the participants gave consent to be audio-recorded. The interviews

varied in length but on average each interview took 45 minutes.

**Table 3.6.1: The link between the objectives, interview questions and probing questions**

<b>OBJECTIVES</b>	<b>QUESTION</b>	<b>PROBING QUESTIONS</b>
To explore the self-management strategies employed by stroke survivors in the Western Cape to address activity limitations.	1. Tell me about your life since your stroke and what you have done to help yourself?	1. Have you had any problem caring for yourself since your stroke?  2. Have you had any problems doing the activities you previously did? Church, work, hobbies?
	2. How have you helped yourself improve function?	3. Keeping fit 3.1 Exercising 3.2 Asking for help 3.3 From family/spouse
To explore the self-management strategies used by stroke survivors in the Western Cape to address participation restrictions.	3. Tell me about your environmental challenges since your stroke	1. Physical Environment 1.1 Have you had any problems navigating a porch/stairs with your assistive device  2. Social Environment 2.1 Do you struggle with socializing? 2.2 Has your relationship with your immediate family changed?



### 3.7 DATA ANALYSIS

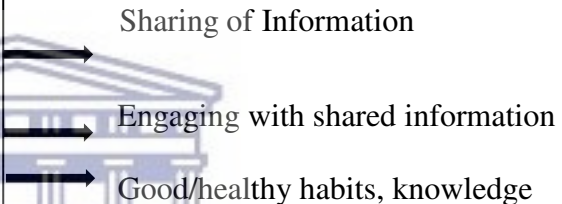
The interviews were transcribed verbatim by an independent transcriber which was then captured into Microsoft Word and checked against the audio- recordings. Transcripts that were not in English were translated to English, first. An inductive thematic approach was used to collect the data; therefore, the themes identified were strongly linked to the data (Patton, 1990). Braun & Clarke’s 6 steps of thematic analysis (2006), was used to analyse the data.

### Step 1: Involves the researcher familiarizing themselves with the data

The researcher familiarized herself with the data by reading and re-reading the data as well as noting down initial codes.

### Step 2: Generating initial codes in a systematic manner

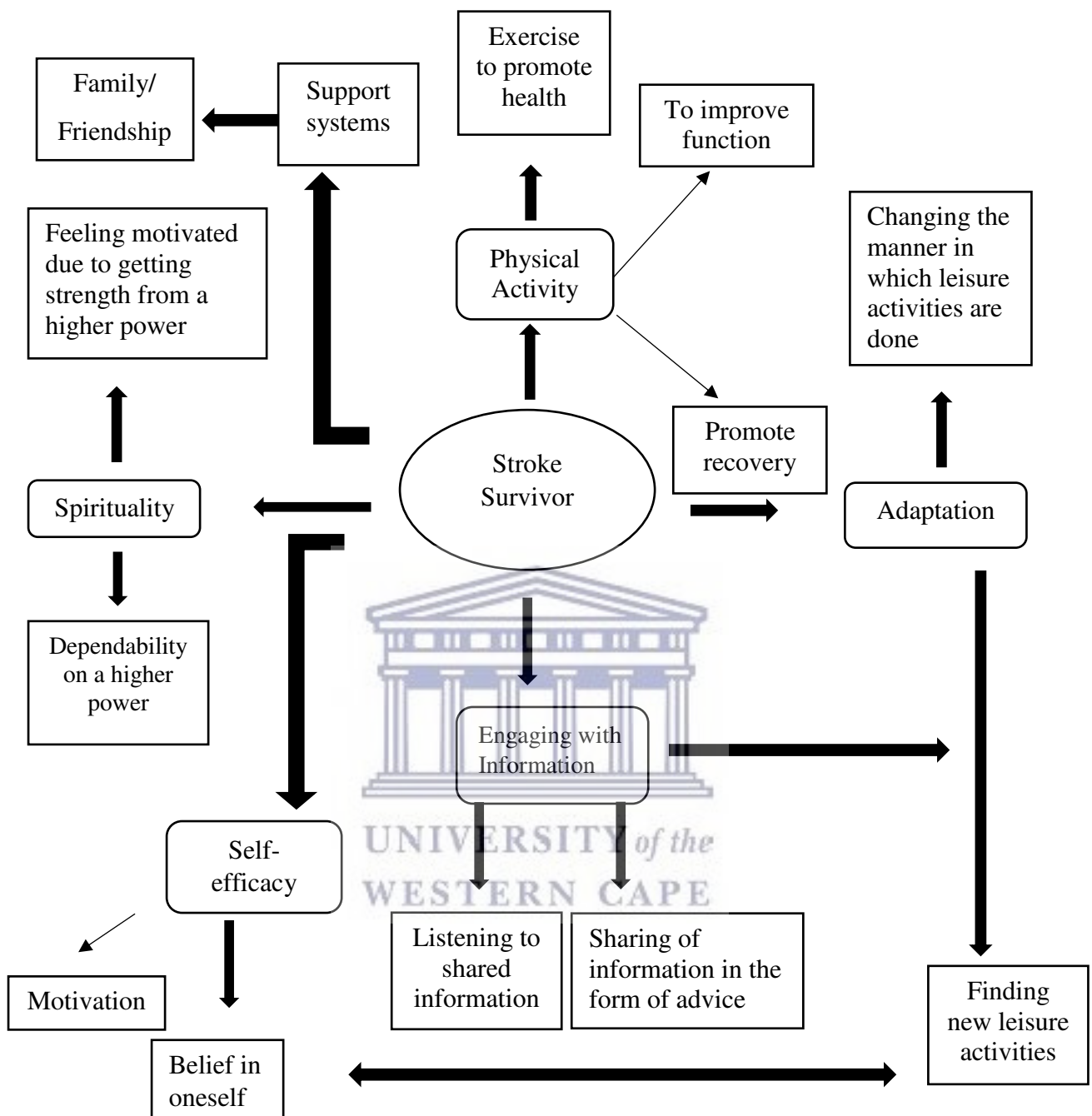
Below is a small extract from one of the interviews which was transcribed verbatim which depicts how the researcher systematically began generating the initial codes for the data. Appendix G is a representation of the codebook from one of the participants' in more detail.

<b>Interviewer:</b> What do you do to help yourself?	
<b>Female Voice:</b> My mother heard from someone that I should eat mebos sweets and so I did that, and you know eating is also good exercise for speech.	

### Step 3: Searching for themes

Searching for themes involved the researcher collating codes into potential themes as well as gathering all data relevant to each potential theme. The researchers' step 3 is illustrated with the use of a thematic map as seen in Figure 3.7.1 below:

**Figure 3.7.1: Searching for themes**



**Step 4: Reviewing the themes**

In Step 4 of Braun and Clarke’s 6 steps of thematic analysis (2006) the themes are reviewed and checked to determine if they are relation to the coded extracts and the entire data set. Below the researcher aimed to link the generated themes to experiences from the extracts of the interviews with the stroke survivors.

**Table 3.7.1: The initial themes of the data and their link to the experiences from the extracts by the stroke survivors**

<b>THEMES IDENTIFIED</b>	<b>EXPERIENCES FROM EXTRACTS:</b>
<b>ADAPTION</b>	<ul style="list-style-type: none"> <li>• Changing previous learned activities</li> <li>• Finding new leisure activities</li> <li>• Challenges in previous learned activities</li> <li>• Environmental challenges</li> </ul>
<b>ENGAGING WITH INFORMATION</b>	<ul style="list-style-type: none"> <li>• Listening to shared information</li> <li>• Information from similar others</li> <li>• Information/assistance from health care professionals</li> <li>• Information from lay persons e.g., family, friends, community members</li> <li>• Engaging with information to better handle my condition</li> </ul>
<b>EXERCISE TO FACILITATE RECOVERY</b>	<ul style="list-style-type: none"> <li>• Exercise to improve function</li> <li>• Exercise to promote health</li> </ul>
<b>SELF-EFFICACY</b>	<ul style="list-style-type: none"> <li>• Motivating oneself</li> <li>• Determining my bodies limitations</li> <li>• Helping me to engage in functional and social activities</li> </ul>
<b>COPING STRATEGIES</b>	<ul style="list-style-type: none"> <li>• Faith/belief in a higher power</li> <li>• Dependability on a higher power for recovery</li> <li>• Spirituality</li> </ul>
<b>SUPPORT SYSTEMS</b>	<ul style="list-style-type: none"> <li>• Family support and understanding</li> <li>• Friendships/family dynamics</li> <li>• Spousal support</li> </ul>

**Step 5: Defining and naming themes**

By refinement of the specifics of each theme, clear definitions and names were given to each theme.

Theme 1: Adaptation

Adaption refers to the participants’ willingness to engage in leisure activities after their stroke by either: (1) changing the activity to how they performed it previously; (2) modifying their

previously learnt activity to engage in daily tasks and (3) developing a new activity to continue engagement in daily tasks in a new way.

### Theme 2: Engaging with information provided

Theme two refers to how the participants sought and engaged with information from various sources, namely by: (1) finding similar others; (2) applying information provided by health professionals and (3) using traditional remedies from the advice of others.

### Theme 3: Coping and acceptance strategies

The participants used three different coping and acceptance strategies to address their activity limitations and participation restrictions. Majority of the participants used their spirituality as a coping mechanism for their loss of ability to function as before. The other two sub-themes which emerged were: support systems and self-efficacy.

### Theme 4: Exercise to facilitate recovery

Participants engaged in exercises to assist with their recovery of function. In order to address activity limitations and participation restriction, two main themes emerged, namely: daily structured exercise and exercise to address the stroke survivors' impairments. Daily structured exercise were taught to participants by a health care professional and participants engaged with these specific exercises to regain function and promote health. The second theme, exercise to address impairments was used to improve function, to address participation restriction and to promote their health.

### **Step 6: Producing the report by selecting extracts (Braun & Clarke, 2006),**

Step 6 will be presented in Chapter 4, in the results section of the report.



### 3.8 TRUSTWORTHINESS

To establish trustworthiness of qualitative data, Shenton (2004) suggested the concepts of as credibility, transferability, dependability and confirmability as essential decisive factors for quality in qualitative research. Therefore, trustworthiness of the analysis was addressed by establishing credibility, transferability, dependability and confirmability.

Tendencies from the transcribed interviews were kept as close as possible to the respondents' own mode of talking (Shepard, 1997) to enhance the credibility of the data. The participants were interviewed in their language of their choice. The researcher did not require the services of a translator at any point during the interview process as the participants were comfortable to be interviewed in either English or Afrikaans. The services of a translator were used for the translation of the transcripts during the research process. To ensure that the data was credible, each interview was recorded and field notes were taken. The researcher conducted the interviews and summarised the interview at the end of the interview. The transcriptions were presented to the participants in a summarized, verbal form based on field notes taken during the interview to ensure that the researcher understood the information provided during the interview by means of member checking (Thomas, 2017).

Credibility, the process by which the findings reflect reality or the truth of the data or the participant views and the interpretation and representation of them by the researcher (Polit & Beck, 2012), was addressed by using an interview guide consisting of similar questions exploring self-management strategies. This was to ensure that the phenomenon studied was clearly operationalized. To further enhance the credibility of the data the themes presented were illustrated with representative quotations from the transcribed texts (Graneheim & Lundman, 2004).



Furthermore, the credibility was enhanced by the sampling variation employed in this study, which allowed for the exploration of rich and broad experiences of self-management practices that took into account the contributions of a range of people (Trochim, 2006).

The transferability of the findings was established by a broad description of the context and systems of care. For this purpose, different characteristics were considered to select participants including living in the community for a minimum of six months post stroke and if participants were able to articulate their experiences. The dependability was strongly enhanced by a description of the informants, questions for data collection and a code-recode procedure followed during data analysis as suggested by Krefting (1991).

Peer examination was done through discussion with experts at the University of the Western Cape who have experience with qualitative data. In order to ensure the confirmability of the data of the study, the experts were required to go through the field notes and transcriptions, data reduction, data reconstruction and thematic categories and interpretations (Lincoln & Guba, 1985). Confirmability was also achieved through the researcher remaining close to the data and presenting direct quotations of informant experiences of self-management strategies employed.

### **3.8.1 Self- Reflexivity**

Reflexivity involves the realisation that qualitative researchers are part of the social world they study and as such, their values, assumptions, prior knowledge and experiences may impinge upon research work (Maritz & Jooste, 2011). Reflexivity during the proposal phase of the study was achieved through bracketing. Bracketing was achieved through dialogue with experts at the University of the Western Cape where the researcher voiced her knowledge and experiences of working with stroke survivors. Reflexivity was achieved during the data collection and data analysis phase, where the researcher kept a reflective or bracketing diary to separate her biases and beliefs.

Reflexivity on the research process as well as investment in the research process is essential. The methodology employed in this study not only allowed stroke survivors to explore their experiences of surviving a stroke in their own voice, it also allowed the researcher, to practice the self-reflexivity necessary for revealing her biases as well as the nature of her understanding of stroke survivors.

The researcher acknowledged that her occupation as a physiotherapist brings with it the bias of knowledge acquired during her student years as well as patient experiences as a qualified physiotherapist. During the data collection phase of the research the researcher found it challenging to come to terms with the impact of the participants' social environment on their overall well-being. However, the reflective diary assisted the researcher to remain focus on the participants' self-management strategies.

Finley (2002) noted that as part of laying claim to the integrity of qualitative research, it is important for researchers, especially novice researchers such as students, to find ways to analyse how subjective and intersubjective elements influence their research. Thus, the researcher used her experiences of her reflective diary to compose a poem (Appendix H). As suggested by Blackwell (2017), of poetry, poetry enables the practitioner to weave all the pieces together so as to bring about learning in a coherent manner.

### **3.9 ETHICAL CONSIDERATIONS**

Ethical clearance was obtained from the UWC Senate Research Ethics Committee (Appendix B). Confidentiality of all participants, whether included or excluded from the study, was ensured by not disclosing any information to unauthorized parties. An information sheet

(Appendix C) were given to the participants to thoroughly inform them about the study with regards to its value and benefits, and clarity on the study was verbally provided to the participants. The patients were also assured of confidentiality and anonymity and they had the right to withdraw from the study at any stage. The transcribed interviews were cited in cryptogram P1-P14 to ensure anonymity was ensured. Signed written consent forms (Appendix D) were obtained from all participants or the participants' guardians/caregivers prior to the interviews to indicate their understanding and voluntary participation in the study. Participants were allowed to withdraw from the study at any stage without any negative consequences. There was no obvious risk involved in participating in the study however, If the questioning evoked emotional disturbances during the duration of the study appropriate referral would take place to a suitable professional for further assistance or intervention. During the study, no participant needed counselling.

### **3.10 SUMMARY OF THE CHAPTER**

In this chapter the research setting was described as well as the health care services in the urban and rural area, respectively. In-depth interviews were used to explore the self-management strategies employed by stroke survivors with reference to the strategies used to address their activity limitations and participation restrictions. After the data was collected a thematic analysis was done. In this chapter the researcher shows step-by-step how she emerged herself and engaged with the data through thematic analysis. Lastly, also in this chapter the ethical considerations pertaining to the study were presented.

# CHAPTER FOUR

## RESULTS

### 4.1 INTRODUCTION

This qualitative study used in-depth interviews to explore the self-management strategies employed by stroke survivors to address activity limitations and participation restrictions. This chapter will start with a description of the interview participants, and will follow with the presentation of the overall theme, its sub-themes and categories which emerged from the transcriptions. In the presentation of the findings, verbatim quotations from interviews will be used. For purposes of anonymity and confidentiality, the transcribed quotations of data from the interviews will be cited in the cryptogram **P1** to **P14**. One participant struggled to articulate her experiences at some point during the interview process, and due to this, her caregiver was interviewed to assist the participant to express her experiences regarding her self-management strategies employed as a stroke survivor. Two other caregivers articulated the day the participants suffered the stroke as the participants could not remember these details. These caregiver responses were disregarded in order to improve the rigour of the study.

### 4.2 DESCRIPTION OF PARTICIPANTS

Nine participants were female (64.3%) and 5 participants were male (35.7%). The participants were aged between 43 and 86 years (mean age =59.6 years). The chronicity of stroke amongst the participants lies between 6 and 120 months (10 years). Majority of the

participants were able to ambulate independently with 78.6%, only 21.4% of the participants used wheelchairs.

**Table 4.2: Demographic data of participants for the study.**

<b>PARTICIPANT NUMBER</b>	<b>SAMPLE</b>	<b>GENDER</b>	<b>AGE</b>	<b>CHRONICITY OF STROKE</b>	<b>AFFECTED SIDE</b>	<b>MODE OF MOBILIY</b>
1	Rural	Female	46	First-ever-3 years, 3 months	L Hemi	Walks independently with 1 crutch
2	Rural	Male	56	First-ever-1 year,4 months	L Hemi	Walks independently with 1 crutch
3	Rural	Female	44	First-ever-5 years	L Hemi	Walks independently with 1 crutch
4	Rural	Female	43	First-ever-9 years	L Hemi	Independent walking
5	Rural	Female	86	Third/more-6 months	L Hemi	Wheelchair dependent
6	Rural	Male	48	First-ever-10 years	R Hemi	Independent walking
7	Rural	Male	66	Second-6 years, 5 months	L Hemi	Walks independently with 1 crutch
8	Rural	Male	59	First-ever-1 year	R Hemi	Wheelchair dependent
9	Rural	Female	62	First-ever-4 years	L Hemi	Uses walking frame at home/ wheelchair in community
10	Urban	Male	73	First-ever-7 months	L Hemi	Walking independently with 1 walking stick
11	Urban	Female	54	First-ever-11 months	R Hemi	Walking independently with 1 walking stick
12	Urban	Female	75	Third stroke/more-8 months	L Hemi	Wheelchair
13	Urban	Female	49	First-ever-7 months	L Hemi	Independent walking

14	Urban	Female	74	Third/more-11 months	R Hemi	Walking independently with 1 quadripod
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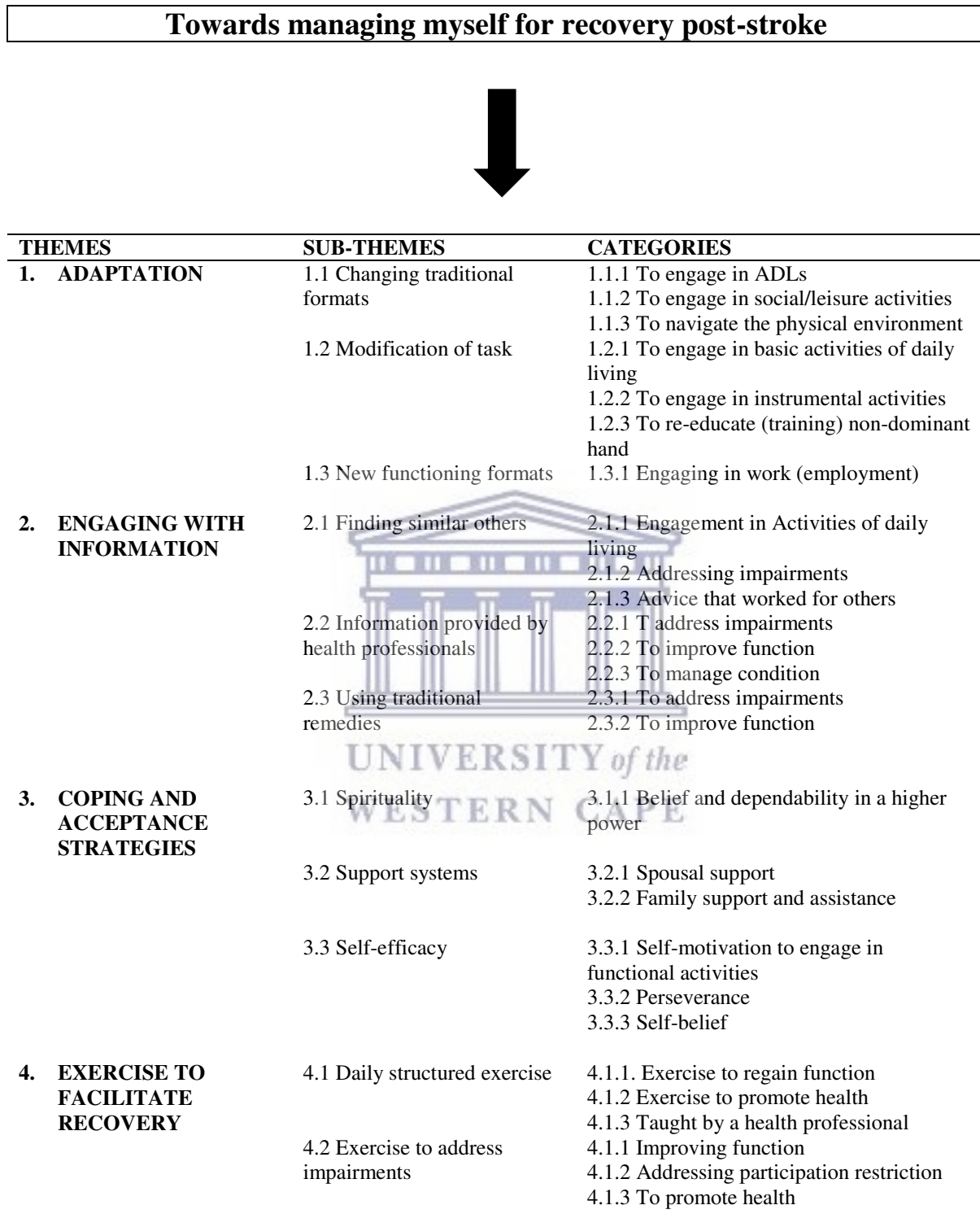
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L=Left; R=Right

### 4.3 QUALITATIVE RESULTS

In the exploration of the self-management strategies employed by stroke survivors living in the Western Cape, to address activity limitations and participation restrictions as conceptualized in the ICF (WHO, 2001), four main sub-themes emerged, namely: adaptation, engaging with information, coping and acceptance strategies, and exercise to facilitate recovery. Participants expressed their journey to recovery as a process of trial-and-error, but also mentioned subjective experiences such as perseverance and sound coping strategies as important to their recovery. Firstly, they expressed the need to “adapt” life to their post stroke capabilities, and by modifying the exterior environment. Secondly, participants shared their views on the importance of engaging with information, which was central to their understanding of their capabilities but also their limitations and restrictions. They found the role of others having lived with stroke to be instrumental to this discourse. Moreover, finding strategies to cope and/or accept their stroke were instrumental to their functioning and the way in which they engaged with the environment. Lastly, the importance of exercise emerged strongly as a facilitator of recovery. Managing life post stroke appears to depend upon multiple strategies executed by the individual living with stroke through active engagement.

**Figure 4.3: A flow chart showing the linkages between the main theme, sub-themes and categories**





### **4.3.1. THEME 1: ADAPTATION**

The participants expressed that they needed to adapt in many ways post stroke. The categories that emerged as part of this theme included, adapting in terms of basic and instrumental ADLs, and engaging in social/ leisure activities, navigating their physical environment as well as work. When engaging with ADLs, the participants either modified the manner in which they conducted the activity, or they asked for assistance from someone else in order to carry out the activity. When engaging in social and/or leisure activities participants mostly changed the way they did their previously learnt format. Participants navigated their environment by changing their traditional formats, by making use of assistive devices and asking for help when they needed it to complete a task within their physical environment. When pertaining to employment, participants had to be innovative by creating new functioning formats in order to be part of the working class.



#### **4.3.1.1 Subtheme 1: Changing traditional formats**

##### **Engaging in activities of daily living**

The participants adapted the manner in which they conducted their ADLs

**P5**                    *“I can’t use the toilet anymore and I am too heavy to lift myself up to use the bedpan. So now I use a commode.”*

**P10**                    *“My wife, in the morning, she used to put water, see that the wood on the bath, a plank. She put a bucket of water for me there and I sit on chair, not on the chair, on the toilet pot and I wash myself.”*

##### **Engaging in social/leisure activities**

The following quote illustrate the participants’ willingness to engage in leisure (or social) and self-care activities after their stroke by adapting to how they performed it previously



**P1** *“I loved socialising with my friends, and dancing... I dance, but now I have to sit and dance.”*

**P3** *“Yes, sometimes when the leg is sore I push myself to church in the wheelchair, other times I walk to church.”*

### ***Navigating the physical environment***

Many of the participants expressed that their environment, namely the terrain surrounding their dwelling posed some challenges. The environmental challenges were mainly addressed through modification of the task at hand.

**P1** *“Yes, there are steps which were also very difficult for me because I was very scared of falling. But eventually I got used to climbing the steps with my crutch, and even when I had the crutch I would always ask someone to walk with me in case I fell so there was someone to help me.”*

**P14** *“Yes, in my house, I’ve got two steps in the passage and if I want to go outside, then I first have to climb on the one and then on the other one with my stick. And the stick helps me a lot because, if I use the stick, then I get as far as I want to be, if I want to walk alone. Sometimes, I try to walk alone then I touch the walls until I get there by the door, then I touch the knob and then the gate and then I get out.”*

Some participants revealed that although they were able to walk, their capacity to walk independently within their home environment had been reduced and that when they fatigued they would sit down to rest, this is represented in the quote below:

**P5** *“I struggle to walk now. I walk with a walking frame but still someone has to walk with me. When I get tired I’ll sit down.”*

#### **4.3.1.2 Subtheme 2: Modification of task**

##### ***Engagement in basic and instrumental activities***

Participants expressed how they modified their engagement in basic and instrumental activities of daily living, namely household activities. This is illustrated below:

**P4**                    *“So after the stroke I put the potato between my legs to help me to peel it.”*

**P10**                    *“I used to do a lot of gardening but at the present, I can’t do it. I can’t do it anymore. I do it but it takes quite a while. My garden is very small now. I don’t have a big garden anymore.”*

**P13**                    *“I couldn’t cut onions. Then I took a knife and pushed the onions and then I used my right hand and cut it. But as I practiced, practiced, practiced, it became better.”*

##### ***Re-education (training) of the non-dominant hand***

Training of the non-dominant hand was also a mechanism used by stroke survivors to adapt, in order to be functional. The following participant was right hand dominant prior to his stroke. Below he expresses how he adapted to use his left hand post-stroke by developing a new way of engaging in activities:

**P9**                    *“I really actually can’t do anything with my right hand. Before the stroke I done everything with the right hand, but the hand is stupid. To feed myself with the left hand is tiring and so on, but I come along with it.”*

#### **4.3.1.3 Subtheme 3: New functioning formats**

##### ***Engaging in work (employment)***

Many participants reported that post-stroke they couldn’t engage in the same work as they did

pre-stroke due to activity limitations experienced.

The following extract shows the thought process participant two is undergoing. Below he is pondering about his previous employment as well as acknowledging his challenges.

*P2                    “Before the stroke, yes, I was a driver. I drove trucks, busses. I don't drive the big stuff anymore, the trucks that would be problem for me I would say...”*

The extract from participant two continues and he expresses his thought process by expressing the need to engage in a different form of employment.

*P2                    “So now we have been thinking, decided to maybe get a permit and start selling fish. But you know, I have to do something, I can't just sit around at home doing nothing.”*



#### **4.3.2. THEME 2: ENGAGING WITH INFORMATION PROVIDED**

The participants expressed that they sought and engaged with information from various sources. The most common sources of information were: finding similar others, applying information provided by health professionals and using traditional remedies from the advice of others. When finding similar others, participants took into account advice from similar others in order to continue to engage in ADLs. The application of information provided by health professionals was applied through addressing their impairments and exercising with the assistance of their families.

##### **4.3.2.1 Subtheme 1: Finding similar others**

###### ***Engagement in activities of daily living and advice that worked for similar others***

Illustrated below is how participants took into account advice from other stroke survivors,

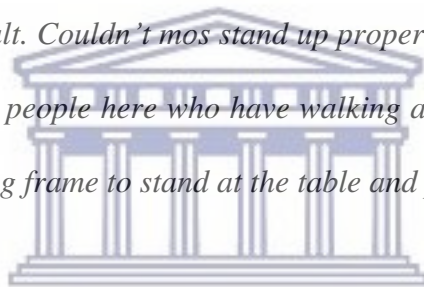
these similar others shared advice on the basis of what worked for them, in order for them to continue to engage in ADLs.

**P1**            *“What I experienced, which isn't the case anymore, is that my left foot starts shaking after I walk for a while. Then I have to put my foot down firmly and wait for the trembling to stop. But that doesn't happen so much anymore. Someone told me, someone who had a stroke before me.”*

#### ***Addressing impairments***

Participant 11 explains what she did to address her impairment of standing by modifying the manner in which she stood as heard by someone that she knew.

**P11**            *“I have done my own exercises here at home. And like us, I have to make some food. It's difficult. Couldn't mos stand up properly. That I am the woman, there are a lot of old people here who have walking aids or things. That I borrowed Auntie's walking frame to stand at the table and push on it.”*



#### ***4.3.2.2 Subtheme 2: Information provided by health care professionals***

#### ***Addressing impairments***

The following quotations show how the participants applied the information provided to them by professionals in order to improve their condition by decreasing their impairments.

**P1**            *“I massaged my weak side with ointment, because the physiotherapists told me that I should remember to do that so my weak side knows it is still part of my body.”*

**P9**            *“What, I'm glad, I've been doing exercises, but I have to do exercises in my own way, and things like that, but with the help of the nurses that show me how to do and what I can do”*

### ***To improve function***

**P3**            *“They told me how I should dress using the paralysed hand, the physio in Grabouw.”*

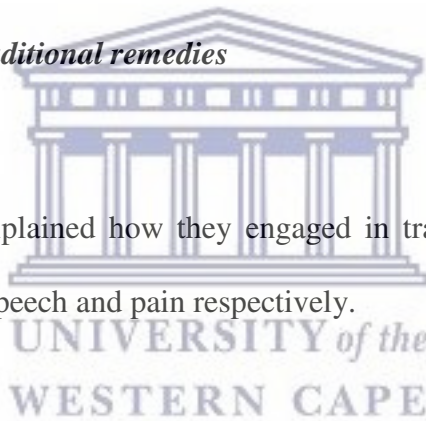
### ***To manage their condition***

**P6**            *“I would say that I also had a lot of guidance from my wife because she just started working as a community health worker at the time and so she gave me a lot of advice. She made it much easier for me and with the help of my two children she could handle it much better because she knew exactly what I needed in my daily life to rehabilitate quicker.”*

#### **4.3.2.3 Subtheme 3: Using traditional remedies**

##### ***Addressing impairments***

The following participants explained how they engaged in traditional remedies in order to address their impairments of speech and pain respectively.



**P1**            *“My mother heard from someone that I should eat mebos<sup>1</sup>\* sweets and so I did that, and you know eating is also a good exercise (for speech).”*

**P14**            *“... One day, a lady across the road, I said to her, ooh, my legs is so sore, my knees. So, she sent me a jar of ointment. This Watkins ointment. And you know, that cost fifty rand for a jar of ointment So, I said, I’m going to give it now. So, she said, you mustn’t send it back, you must keep if for yourself.”*

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<sup>1</sup> \*Mebos- A Cape Malay preserve made from dried apricots and other fruit, pulped or flattened.

### **4.3.3 THEME 3: COPING AND ACCEPTANCE STRATEGIES**

The participants used three different coping and acceptance strategies to address their activity limitations and participation restrictions. Majority of the participants used their spirituality as a coping mechanism for their loss of ability to function as before. The other two sub-themes which emerged were: support systems and self-efficacy. The categories which came out of the sub-theme, support systems, were spousal support, and support and assistance from family. The participants exhibited self-efficacy by motivating themselves, by persevering in challenging situations as well as believing in themselves.

#### **4.3.3.1 Subtheme 1: Spirituality**

##### ***Belief and dependability in a higher power***

The participants enlightened the researcher to how their belief in a higher power served as a coping mechanism for their health condition. Below the participants expressed that they were confident that the God they believed in would assist them with their recovery.

**P1**            *“Even if it doesn't get better, I know it will get better one day in heaven. I am satisfied.”*

**P8**            *“I am very grateful to God. He was the one. God was the one who encouraged me and gave me the willpower to exercise and exercise and to never give up.”*

Participants expressed that they were dependent on a higher power to assist them in regaining the function they had lost when they suffered their stroke.

**P14**           *“I said, the Lord is going to help me. I'm going to walk again. I'm going to do things again like I used to do.”*

#### **4.3.3.2 Subtheme 2: Support Systems**

##### ***Spousal support***

The following participant illustrates how his wife now has to assist him in navigating his outside environment due to a previous fall.

**P2**            *“No, there aren't any steps, just a steep hill, and you know, sometimes there is loose gravel and then you can slip. I could probably walk up there, but my wife stops me because I did fall once.”*

The following participant explains that he received enough support from his family and friends. He further illustrates that the support he received from his wife was important because she was able to remember key information that a health care professional told them at the hospital.

**P10**            *“I got enough support. Especially from the wife. Oh, she’s really...sometimes I walk and I want to walk, then she says, “No! Wait.” They told her at the hospital, this physiotherapist. He told her that I must first stand before I start walking.”*

##### ***Family support and assistance***

The following participant emphasised that she received the most support from her sister in law in the form of assistance in her activities of daily living. She also expressed how her family supported her by assisting her in activities of daily living, especially with assisting her to the bathroom.

**P13**            *“And my sister in law, they always helped me, like going to the bathroom and things like that. They helped a lot.”*



#### **4.3.3.3 Subtheme 3: Self-efficacy**

##### ***Self-motivation to engage in functional activities***

The participants exhibited self-efficacy and enlightened the researcher as to how they motivated themselves to engage in functional activities through. This is illustrated below:

**P2**            *“At first when I was in the chair I never believed that I would be able to do those things again, but I just persevered with the exercises they gave me there. After the stroke, in the beginning when I felt I was not alright, it was quite depressing for me. I felt down. I was in the wheelchair for about four days, and that was when I almost lost hope completely. But then I decided to get up and make the best of a bad situation. And then after the fourth day, the fifth day I got up and walked.”*

**P10**            *“Do something for yourself to give you more confidence that you can do these things, otherwise, nobody’s going to help. They trying to help you but you the one that must always help yourself.”*

##### ***Perseverance***

The participant’s is describing her activities and in her own opinion how she demonstrated perseverance.

**P11**            *“I used to motivate herself by uplifting herself and told myself that she won’t lay. Like I would walk step by step to the toilet even if it took forever, I just did it.*

The next participants demonstrated the willingness to continue to try and never to give up.



**P7** *“They couldn't believe that I was progressing so fast. But it wasn't due to them, I worked on my own. They were surprised but it wasn't due to them because sjoie they only came here once a month.”*

**P14** *“Sometimes I try. I must try also to do something. You can't let somebody do everything. Because everybody tell me, haai, you got a stroke but a person won't say you had a stroke because you still look the same.”*

### ***Self-belief***

Subsequently, the following participant depicts that self-belief is important on the road to recovery post stroke

**P7** *“I want to suggest they be doing as well. And is to believe you can, believe you can survive. The stroke isn't the end of it all. It isn't.”*

## **4.3.4 THEME 4: EXERCISE TO FACILITATE RECOVERY**

Participants engaged in exercises to assist with their recovery of function. In order to address activity limitations and participation restriction, two main themes emerged, namely: daily structured exercise and exercise to address impairment. Daily structured exercise were taught to participants by a health care professional and participants engaged with these specific exercises to regain function and promote health. The second theme, exercise to facilitate recovery was used to improve function, to address participation restriction and to promote their health.

### **4.3.4.1 Subtheme 1: Daily structured exercise**

#### ***Exercise to regain function***

The participants explained how they engaged in daily structured exercise to in order to regain function.

**P7** *“But then I worked the arm, I worked the arm. I took this right hand, I lift up this one. I was lying, I would lift it up every day, every day till eventually I saw but yes my arm is now moving as well-ok great.”*

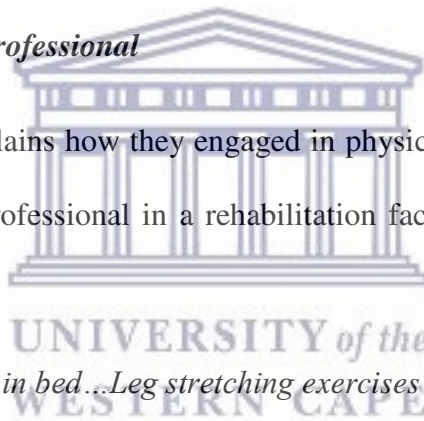
***Exercise to promote health taught to the participants by a health professional***

Participant 13 reported on exercises that she did in order to address specific impairments through structured exercise taught to her by a health professional. This is illustrated below.

**P13** *“For the fine motor response for your fingertips, then they always got these 10 cent coins, then you sit. You're struggling to pick up 10 cents because your hand is not right, you can't feel it. All these strange things.”*

***Exercise taught by a health professional***

The following participant explains how they engaged in physical activity after discharged as taught to them by a health professional in a rehabilitation facility in order to address their impairments.



**P5** *“I do exercises in bed...Leg stretching exercises and what else? And lifting the arms up and down, yes. And the legs up and down, up and down. Just like they make it to me in rehab.”*

The following participant explains that health care professionals used the participants' interest in sport to guide the participants' treatment.

**P6** *“The medical officer told me, asked if I was very sporty, I told him yes, then he said to me but it would be good if I had to start seriously again with my sport, so I could relax more...”*

***Exercise to promote health***

The participant then goes on to explain that he employed the strategy of exercise to maintain recovery and promote his health.

*P6* “...I just do ordinary stretching exercises, try to relax as much as possible. I try not to run too far, but just far enough to enjoy myself.”

#### **4.3.4.2 Subtheme 2: Exercise to address impairments**

##### ***Improving function***

Participant 10 explains that he did resistance exercises in order to gain strength so he could improve his functioning.

*P10* “Mostly doing the weights. Picking up weights and the exercises of the hands. My wife had a roll out, print some of those exercises for me, because my hands, I couldn't ... and sometimes it feels like if it's a ... I can't touch it too much.”

##### ***Addressing participation restriction***

Participant 12 explains her manner of exercising in order to address the limbs of the affected side.

*P12* “I just tried to keep cups. I tried to hold on to something. I've tried, for example, to put my foot down, to put pressure on it so that I can get some help. I tried to take my hand and make it hold things.”

##### ***To promote health***

The following participant explains that she engages in a weekly exercise programme to keep fit. She also ensures that she takes care of herself in order to prevent another stroke.

**P4**            *“Here at Mind over Matter we receive physio every Thursday from the Dutch people who are physios, they show us exercises... and they say, after you have your first stroke, chances are you'll have another one, but for 11 years I haven't had another stroke. And I look after my health alone, no one else does it.”*

#### **4.4 SUMMARY OF THE CHAPTER**

In this chapter the qualitative results were described, and the four main themes were discussed. The four main themes were: adaptation, engaging with information, coping and acceptance strategies and exercise to facilitate functioning. The chapter discussing the results will follow.



# CHAPTER FIVE

## DISCUSSION

### 5.1 INTRODUCTION

This chapter will discuss the findings of the study with reference to relevant literature. The findings will be discussed under the following main sections: adaptation, engaging with information provided, coping and acceptance strategies, exercise to facilitate recovery, the role of rehabilitation professionals, and sampling. The limitations of the study will also be presented in this chapter.

### 5.2 QUALITATIVE DISCUSSION

The aim of the study was to explore the self-management strategies employed to facilitate functioning by stroke survivors living in the Western Cape, South Africa, specifically with regards to their activity limitations and participation restrictions as conceptualized within the ICF (WHO, 2011).

To function within the community, stroke survivors implement adaptive behaviours. Stroke survivors exhibit multiple strategies to remain independent, particularly at the level of activity limitations and participation restrictions. The stroke survivors who participated in the current study implemented four main self-management strategies, namely: adaptation, engaging with information, coping and acceptance strategies and exercise to facilitate functioning. These strategies were implemented to assist functioning within their home environment and to decrease the impact of their physical environment on their functioning.

These skills and abilities are necessary for managing the impairments and participation restrictions post stroke, their roles and responsibilities within home and community life, and their emotional (mental) health. These adaptive strategies are directly linked to the stroke survivors' ability to participate in their environment and to address their activity limitations.

### **5.2.1 Adaptation**

When engaging in ADLs the participants expressed the need to modify the manner in which they conducted the activity or to ask for assistance from someone else in order to carry out the activity. Participants particularly articulated that post stroke they had to adapt the manner in which they walked. Many participants expressed that post stroke they would need an assistive device to assist them in walking. This finding is echoed in Beauchamp et al. (2009), in that post-stroke participants commonly use walking aids to achieve independent gait. In the South African context, the appropriate assistive device is not always available due to the limited resources in the country. Rehabilitation service delivery in developing countries and especially in rural settings are very challenging (Eklund, 2006; Strait, 2006; WHO, 2011a).

Some of these problems include:

- 1) inaccessibility of health care services,
- 2) systemic barriers,
- 3) lack of trained rehabilitation personnel to provide rehabilitation services,
- 4) inappropriate preparation of health care personnel for rural settings,
- 5) difficulty attracting and retaining staff,
- 6) lack of coordinated multidisciplinary services,
- 7) inappropriate assistive devices, and
- 8) lack of research and evidence-based practice (Eklund, 2006; Strait, 2006; WHO, 2005; WHO, 2011a; WHO, 2011b).

Participants also expressed that although they could navigate their environment post stroke with an assistive device they felt safer when someone was walking alongside them to assist them if they needed help or if were about to fall down. Related findings were reported by Cunningham and Rhoda (2014) in which participants expressed that they were able to navigate environmental features such as stairs with the assistance of someone.

The functioning within the parameter of adaptation for stroke survivors: what emerged strongly from this sub-theme was the influence of the environment in determining one's functioning. The environmental barriers identified in this study related to features such as stairs and uneven surfaces, especially in and around the participants' dwellings. The participants navigated these challenges by means of adaptation. They either asked for help from someone or modified the manner in which they previously climbed stairs by using an assistive device. Participants reported that even though they were able to navigate the steps successfully they felt more comfortable when someone was there to assist them as their fear of fear of falling was heightened when they encountered environmental features such as steps. Dowswell, Lawler, Dowswell, Young, Forster, & Hearn (2000), found that physical obstacles and fear of falling decreased activity levels, which then further resulted in participation restrictions due to decreased social interaction. Participants from this study agreed that navigating their physical environment was challenging. It is therefore important to have knowledge of the environments and contexts these individuals find themselves in. This knowledge of the context of the individuals is also important as rehabilitation professionals guide and support any adaptations that could be implemented in order to assist functioning.

### 5.2.2 Engaging with Information Provided

Participants from this study engaged with information from different sources. The participants raised the importance of seeking similar others and engaging with the information these similar others had to offer. More often than not the participants actively employed the information shared from the similar others as opposed to information provided by a health care professional. In a novel study by Jones, Mandy and Partridge (2009), the authors acknowledged that the information provided by the stroke survivors was fundamental in the restructuring of the Bridges SSMP, even though, the authors used information from stroke survivors, carers and professionals to further improve their Bridges SSMP for stroke survivors after their initial development of the SSMP. This suggests that the stories shared by other stroke survivors is a powerful tool for newly affected persons with stroke. These stories may very well equip those who are involved in a stroke survivor's journey with powerful insight to their journey (Thomas, Allison, & Latour, 2018).

Participants from this study engaged with information from different sources. Jones and Brimicombe (2014) acknowledged that SSMP are the most effective when they employ a whole system approach. This suggests that a team approach is necessary and more effective in the treatment of stroke meaning that the stroke survivor and the carer should be active members of the multidisciplinary team.

It is clear that participants who have suffered a stroke need access to health information in order to better manage their recovery post stroke. In an article by Du, Ma and Li (2016), the researchers noted that as the stroke survivors' journey to recovery evolves; participants' needs or preferences for health information at different stages of stroke vary individually, and change over time. Health care professionals should also be aware of the different methods for



providing information to participants with stroke and the participants' different preferences for the format of information delivery (Savage, Arif, Smoke, & Farrell, 2017). Due to this change and complex recovery greater efforts need to be made to actively involve stroke participants in information seeking, and the most suitable method(s) to provide health information which is sensitive to the participants' individual needs (Rodgers, Bond, & Curless, 2001).

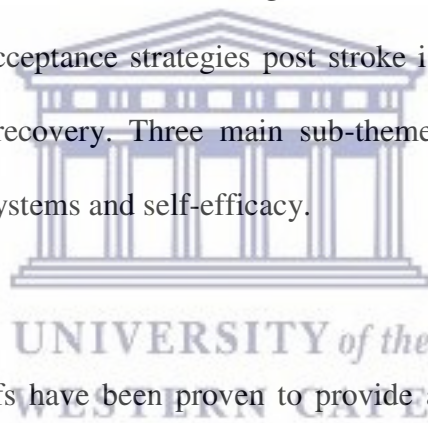
The role of rehabilitation professionals in a self-management context is to provide support for the self-management strategies employed by individuals with stroke (Gibson et al., 2000; Jovicic, 2006; Zwerink et al., 2014). It further provides information on the unmet needs of survivors which could be addressed by relating current strategies employed to address limitations and restrictions. Results from this study highlights the importance of recognizing that information is an essential part of an individual's rehabilitation to facilitate better functioning. Enabling self-management behaviours is considered important in order to develop coping strategies and confidence for managing life with a long-term condition (McKenna, Jones, Glenfield, & Lennon, 2015).

Although, Gibson et al. (2000); Jovicic (2006) and Zwerink et al. (2014), have found that self-management has been linked to lessen the use of the health care system with regards to the capacity of health care providers and increasing cost as well as to help participants manage their health more effectively (Boger, Demain, & Latter, 2012), the benefits of the Bridges self-management programme specifically for stroke survivors is not well documented. The major benefit of the Bridges stroke self-management programme is to support individuals once rehabilitation stops, to assist stroke survivors in successfully adjusting and self-managing life with a stroke (Jones & Brimicombe, 2014). Other benefits of the Bridges stroke self-management programme is the impact of key outcomes relating to confidence, mood and functional capability (Jones, McKeivitt, Riazi, & Liston, 2017). This

suggests that self-management programmes could bridge the gap by further expanding the survivors functioning.

### **5.2.3 Coping and Acceptance Strategies**

The interaction of the themes found in this study highlights the complexity of life after stroke and the ability of individuals to use resources, both internal and external, in expanding their independency, autonomy and functioning. This complexity is highlighted in a systematic review by Donnellan, Hevey, Hickey and O'Neill (2006), the researcher found that there was conflicting research with regards to coping strategies employed post stroke. Donnellan et al, (2006) reported that they were unable to conclusively identify specifically what strategies stroke survivors employ over the short and/or long term but that they were able to identify general trends. Coping and acceptance strategies post stroke is an important internal factor which positively influences recovery. Three main sub-themes emerged from this theme, namely: spirituality, support systems and self-efficacy.



Spirituality or religious beliefs have been proven to provide a stable cognitive framework from which to make meaning of and integrate a traumatic event. (Overcash, Calhoun, Cann, & Tedeschi, 1996). As such, participants in this study used spirituality as a coping mechanism and an acceptance strategy for their post stroke recovery. The categories that emerged from the sub-theme spirituality included a belief in a higher power and dependability on a higher power, the higher power being namely, God. The participants in this study used their relationship with their God in a variety functions, such as encouragement to recover and for inner strength. This is similar to the findings of Gall and Cornblat (2002) where breast cancer survivors used their religious/spiritual belief in a higher power as a stable resource which served to encourage greater inner strength or faith in self; as a provider for

guidance in life decisions; as a supporter of the process of personal growth from a crisis which leads one to a positive attitude of acceptance.

The participants expressed that spousal and family support was instrumental in their long-term engagement with ADLs and in their post-stroke recovery. A study by Lynch et al. (2008) found that social support in the form of social relationships is of paramount importance if one is to survive the long-term effects of a stroke. In a study by Huang, Hsu, Hsu, Cheng, Lin, and Chaung (2010), the researchers found that increased social support is directly linked to increased quality of life. The support the stroke survivors received assisted them in reaching their fullest potential in terms of their physical, psychological, social, vocational and educational potential within the limits of the stroke survivors' physiological and anatomical impairments (Barker, 2008).

In contrast, it was found that poor social support has been linked to poor quality of life post stroke (Mackenzie & Chang, 2002). This is believed to be influenced by the functional and cognitive state (Mackenzie & Chang, 2002); therefore, the burden of stroke highlights the need for greater social support (Huang et al., 2010).

The participants of this study exhibited self-efficacy in three ways, namely: self-motivation (motivating themselves to engage in functional activities); perseverance (by trying, trying and trying again an activity), and self-belief (finding greater inner strength). The participants use the strategy of self-efficacy to facilitate recovery and to reduce their impairments post stroke. This is in echoing the sentiments of the studies Theoretical framework (Banduras Social cognitive theory (1997)) , that self-efficacy is the focal determinant of functional adaptation for it affects outcomes both directly and by influencing other intrapersonal factors such as goals, outcome expectations, and self-evaluative reactions to one's behaviour and resulting outcomes.

Participants expressed that initially after they suffered a stroke, they felt depressed. However, after exhibiting self-efficacy through self-motivation they decided to take control of their condition and reduce their impairments through exercise. A similar finding was established in a study by Korpershoek, van der Bijl and Hafsteinsdóttir (2011), which stated that individuals with stroke with higher self-efficacy can gain more control over important aspects of their medical condition, which might enhance their independence in daily living and decrease the level of depression.

In a 2013 study by Burton, who interviewed six participants over a 12 month period, exploring participant's physical, social and emotional experiences found that participants placed more value on social engagement than physical recovery.

#### **5.2.4 Exercise to Facilitate Recovery**

The participants in this study engaged in exercise to facilitate their recovery and regain function. Participants also used exercise as a strategy to maintain the existing function. In a study which measure the participation in leisure activity and exercise of chronic stroke survivors (Yi, Han, Lee, & Ha, 2015), found that exercise duration post stroke increased, which is contradictory to the findings of Rimmer, Wang and Smith (2008), which found that exercise duration post stroke was significantly decreased. In a study by Langhorne, Bernhardt and Kwakkel (2011), the researcher found that physiotherapy intervention is primarily aimed at restoring and maintaining ADLs through specific exercise to address the participants' impairments, usually starting within the first days and often continuing into the chronic phase post stroke.

It was found that participants not only engaged in general exercise but also engaged in specific exercises given to them by a health care professional. A synthesis by Hillier and

Inglis-Jassiem (2010), tested the hypothesis that home rehabilitation would cost less than clinic-based care but would not compromise recovery. Eleven trials of single discipline physiotherapy, or occupational therapy, or multidisciplinary care, involving 1711 adults within 12 months of stroke were identified. Four of the 11 trials found no difference between home and outpatient care; the remaining seven trials showed greater benefit for home rehabilitation in terms of cost, satisfaction, and caregiver strain. This is an important finding, particularly in the context of South Africa, with its low rehabilitation sources. This highlights the importance and need of effective home exercise programmes for stroke survivors.

Participants explained that they used exercise as a strategy to relax, to build up their strength as well as to improve their cardiovascular endurance. Participants further explained that they engaged in specific exercises to improve their co-ordination. This is relevant to clinical research on the benefits of exercise for stroke. The researchers found that: (1) Aerobic exercise, may play an important role in improving aerobic fitness, cognitive abilities, quality of life, mobility, and other health outcomes among stroke participants. (2) Strength exercise, included in national stroke guidelines and recommended for general health promotion for stroke survivors, can lead to improvements in functionality, psychosocial aspects, and quality of life for post-stroke participants. (3) Flexibility exercises can relieve muscle spasticity problems, improve motor function, range of motion, and prevent contractures. (4) Stretching exercises can also prevent joint contractures, muscle shortening, decrease spasticity, reduce joint stiffness and improve a post-stroke patient's overall function. (5) Neuromuscular exercises can improve activities of daily living (ADL) through coordination and balance activities (Han et al., 2017).


In a study by Hammer, Bieler, Nina and Midtgaard (2016) conclusions were drawn that linked perceived self-efficacy for physical activity to the understanding of post-intervention physical activity maintenance in patients with hip osteoarthritis. The study links one source of

self-efficacy namely, verbal persuasion, disease-specific information and an individualized training programme to experiences of success. This suggests that self-efficacy plays a role in perceived successful exercise outcomes which relates to this studies theoretical framework. The study by Hammer, Bieler, Nina and Midtgaard (2016) also shows a direct link between exercise, information and self-efficacy (identified as a coping strategy) which are three of the four main themes identified from the participants in this study.

What exactly does self-management mean in the context of the diversity of SA? Are the participants of SA on the road to better self-management? Stroke survivors use self-management strategies for their medical, social and psychological needs. Further research is required to explore the role of spirituality in rehabilitation.

### 5.3 Limitations

Data Collection:

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- During the data collection from the urban sample, many participants were excluded due to the participants residing in an area that is considered a red zone, namely Tafelsig, Mitchells Plain. The red-zone areas are where ambulance crews are often attacked (Phaliso, 2017). The suburb of Mitchells Plain was second in the top 10 worst precincts in the province of the Western Cape in 2017 with a total number of 31 484 number of reported crimes in the area. Crime Stats SA, 2017). As a result, selection bias arose. The participants from the excluded area could have provided the researcher with their experiences as stroke survivors residing in an area with an extremely high crime rate. These stroke survivors could have opposing experiences to those not residing in an area with an extremely high crime rate.
  - Another factor for inclusion into the study was that participants needed to be

orientated to time and place. Participants who were aphasic expressive and/or aphasic receptive had to be excluded from the study if they could not provide clear answers during the face-to-face interviews. These excluded participants could have provided the researcher with their experiences as a stroke survivor.

- Qualitative research is an interpretive process and representation is an individualised process which could influence the data through the bias of the researcher.
- It is noted that one of the limitations to this study was that some of the telephone numbers given to Life Esidimeni Intermediate Care were either incorrect, changed, or disconnected; greatly decreasing the pool of potential participants
- The findings of the study are more related to stroke survivors who are higher functioning as ten of the fourteen participants were ambulatory. Stroke survivors who are wheelchair dependent might exhibit different self-management strategies to stroke survivors who are ambulatory.



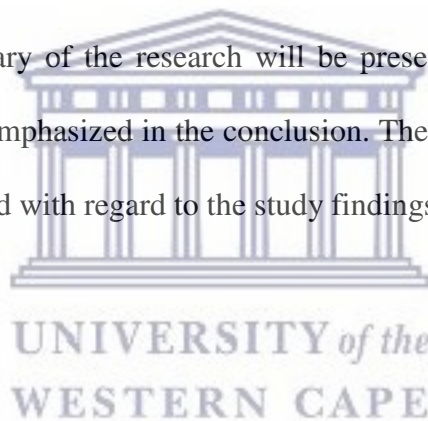


## **CHAPTER SIX**

### **SUMMARY, CONCLUSION, IMPLICATIONS FOR PRACTICE AND RECOMMENDATIONS**

#### **6.1 INTRODUCTION**

In the final chapter, a summary of the research will be presented, and the most important findings of the study will be emphasized in the conclusion. The chapter concludes by making recommendations that emerged with regard to the study findings.



#### **6.2 SUMMARY**

The study aimed to explore the self-management strategies employed by stroke survivors in the Western Cape, South Africa to address their activity limitations and participation restrictions.

An exploratory, qualitative design was employed as overarching methodology to describe self-management strategies amongst stroke survivors.

Participants were recruited from an urban and rural area in the Western Cape. An interview guide was developed based on previous literature. An in-depth interview was conducted to collect the experiences of the stroke survivors and a total of 14 participants were interviewed. The participants' interviews were audiotaped during the interview process. Their audiotapes



were then transcribed verbatim. The interviews that were conducted in Afrikaans was transcribed and then subsequently translated into English. Braun and Clark's 6 step thematic analysis was used to analysis the data. Ethical clearance was sought from the UWC research ethics committee.

The results found that participants exhibited four main encompassing strategies to facilitate their recovery. The four main strategies identified by the participants' experiences were: adaptation, engaging with information, coping and acceptance strategies, and exercise to facilitate recovery. The sub-themes identified within the theme of adaptation were: 1) changing traditional formats, 2) modification of the task and 3) new functioning formats. The sub-themes identified within the theme of, engaging with information, were: 1) finding similar others, 2) information provided by health professionals and 3) traditional remedies. The sub-themes identified within the theme of, coping and acceptance strategies, were: 1) spirituality, 2) support systems and self-efficacy. The sub-theme identified within the theme, exercise to facilitate recovery were: 1) daily structured exercise and 2) exercise to address impairments.

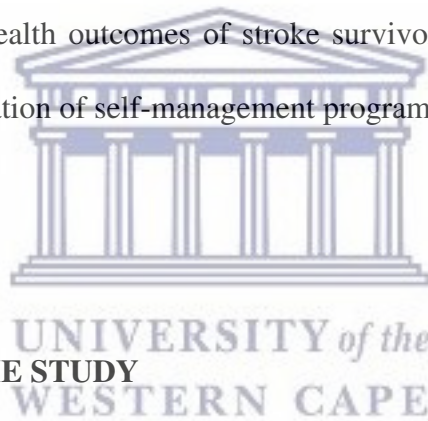
The relationship of the themes found in this study pinpoints the complexity of life after one experiences a stroke. The interaction of themes also highlights the ability of individuals to use internal and external resources in expanding their independency and functioning post stroke.

The results indicated that to function within the community and their home environment stroke survivors implement multiple strategies. These strategies are exhibited to remain independent and facilitate functioning, mainly at the level of activity limitations.

### **6.3 CONCLUSION**

The aim of the study, was to determine what the strategies are that stroke survivors employed to facilitate functioning in the Western Cape, this was successfully achieved. Stroke survivors

exhibit multiple strategies to remain independent and facilitate functioning, mainly at the level of activity limitations. In order to engage in functional and function within their communities, stroke survivors implemented four main strategies, namely: adaptation, engaging with information provided, coping and acceptance strategies and exercise to facilitate recovery. The findings of this study are more related to higher functioning stroke survivors as ten out of fourteen of the participants of the study were ambulatory. Therefore, rehabilitation should offer newly affected persons with stroke more encompassing strategies in order to live a full, effective life as the role of rehabilitation professionals in a self-management context is to provide support for the self-management strategies employed by stroke survivors. The benefit of this research is that rehabilitation of stroke survivors could be informed which would positively contribute to the health outcomes of stroke survivors living in the community as well as inform the implementation of self-management programmes for stroke survivors in the context of South Africa.



#### **6.4 SIGNIFICANCE OF THE STUDY**

Self-management support strategies provided during the rehabilitation of individuals with stroke should be contextual to facilitate their functioning in their communities. Physiotherapists should also engage aspects relating to internal motivators, such as self-efficacy and spirituality which could enhance self-belief and resilience.

The role of spirituality in the rehabilitation of stroke participants needs to be considered during the rehabilitation of individuals post stroke. Stroke survivors used both internal motivators (such as, belief in oneself and, dependability and belief in a higher power) and external motivators (such as the use of similar others) to cope with life after stroke. This highlight the need to be aware of these aspects during the rehabilitation process in order to

promote recovery. Furthermore, health professionals, researchers and fellow academics need to promote effective participation based on the United Nations Convention on the Rights of Persons with Disabilities: (UNCRPD).

## **6.5 RECOMMENDATIONS**

### **6.5.1 Recommendations for Practice**

From the study findings and conclusion, it is therefore recommended that the role of spirituality in the rehabilitation of stroke participants needs to be considered during the rehabilitation of individuals post stroke.

### **6.5.2 Recommendations for Research**

The study findings noted that the implementation of self-management programmes specifically focussing on stroke is not well documented, therefore further research needs to be done to explore the implementation of such programmes.

The study findings also noted that participants used internal motivators such as dependability on a higher power to cope with life post stroke and it is therefore recommended that the role of spirituality in rehabilitation be explored further.

A limitation of this study was the exclusion of stroke survivors in an area with an extremely high crime rate. Further research needs to be done to explore the experiences of participants living in areas with a high crime rate.

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# APPENDICES



## APPENDIX A: MODEL OF DISABILITY

### UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

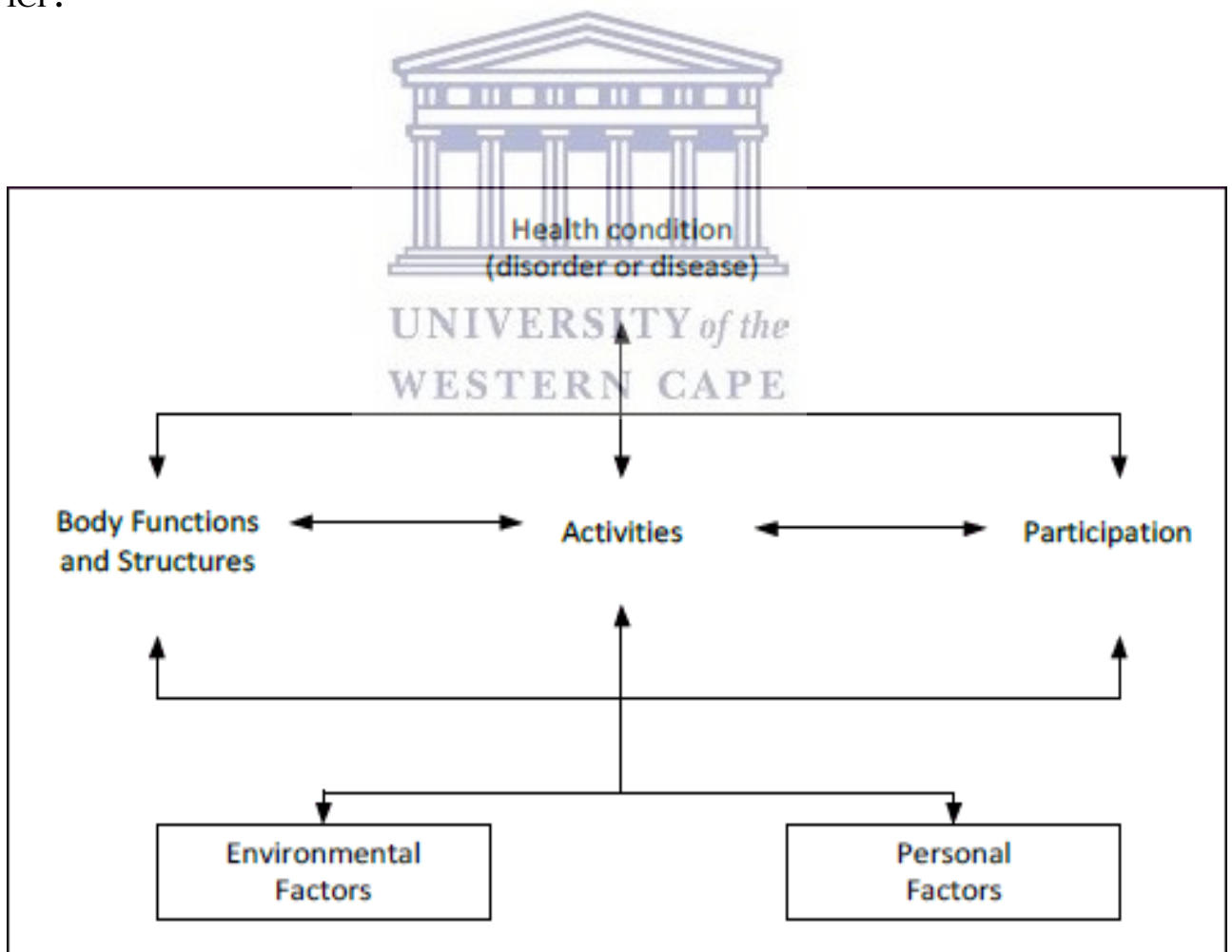
Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail: [3152194@myuwc.ac.za](mailto:3152194@myuwc.ac.za)

#### MODEL OF DISABILITY

#### ICF MODEL

The following diagram is one representation of the model of disability that is the basis for ICF:





## **APPENDIX B: ETHICAL CLEARANCE FROM UWC**



OFFICE OF THE DIRECTOR: RESEARCH  
RESEARCH AND INNOVATION DIVISION

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22 August 2016

Ms JL Smith  
Physiotherapy  
Faculty of Community and Health Sciences

**Ethics Reference Number** HS/16/5/39

**Project Title:** Self-management strategies employed by stroke survivors in the Western Cape, South Africa.

**Approval Period:** 29 July 2016 – 29 July 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.

A handwritten signature in black ink, appearing to read 'Patricia Josias', is written over a faint background watermark of a classical building facade.

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

**PROVISIONAL REC NUMBER - 130416-049**



## APPENDIX C: INFORMATION SHEET

# 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: [3152194@myuwc.ac.za](mailto:3152194@myuwc.ac.za)

## INFORMATION SHEET

**Project Title: Self-management strategies employed by stroke survivors in the Western Cape, South Africa**

### **What is this study about?**

This is a research project being conducted by Janine Smith at the University of the Western Cape. I am inviting you to participate in this research project because you have survived a stroke. The purpose of this research project is to explore the challenges you have experienced after your stroke and how you have helped yourself cope with these changes.

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

You will be asked to participate in a one-on-one interview with the researcher. This will take place at a time and place that is convenient for you in your local language. You will be audio-taped. Questions will be asked about the challenges you have experienced after you have suffered your stroke. After the transcriptions have been translated the researcher will visit you again at a time and place that is convenient for you and present you with the data. This is done to ensure that what was transcribed is what you meant to say.

### **Would my participation in this study be kept confidential?**

The researchers undertake to protect your identity and the nature of your contribution

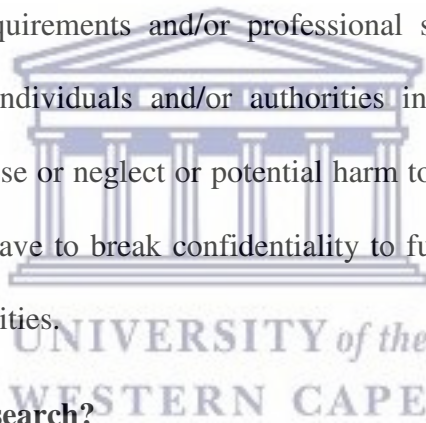
To ensure your confidentiality:

(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.

If the researcher writes a report or article about this research project, your identity will be protected to the maximum extent possible.

In accordance with legal requirements and/or professional standards, the researcher will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.



**What are the risks of this research?**

There may be some risks from participating in this research study. All human interactions and talking about yourself or others carry some amount of risks. The researcher 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 researcher learn more about the challenges experienced by stroke survivors and how they have coped with them. The researcher envisions that 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 by informing future rehabilitation with post-stroke.

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 Janine Smith from the Physiotherapy department at the University of the Western Cape. If you have any questions about the research study itself, please contact the researcher, Janine Smith at: [3152194@myuwc.ac.za](mailto:3152194@myuwc.ac.za), the department on: 021 959 2542 or the supervisor, Professor Anthea Rhoda at: [arhoda@uwc.ac.za](mailto:arhoda@uwc.ac.za).

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:

Dr Nondwe Mlenzana

Head of Department: Physiotherapy

University of the Western Cape

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Bellville 7535

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**APPENDIX D: CONSENT FORM**



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**CONSENT FORM**

**Title of Research Project: Self-management strategies employed by stroke survivors in the Western Cape, South Africa**

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.....

Witness.....Witness signature.....

## APPENDIX E: INTERVIEW GUIDE FOR PATIENTS



# UNIVERSITY OF THE WESTERN CAPE

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1. Tell me about your life since your stroke and what you have done to help yourself?

### Probes:

- Have you had any problems caring for yourself since your stroke?
- Have you had any problems doing the activities you previously did? Eg. Church, work, hobbies?

2. Tell me about your environmental challenges since your stroke?

### Probes:

- Physical Environment
- Social Environment



3. How have you helped yourself improve function?

### Probes:

- Keeping fit (Exercising)
- Asking for help



**APPENDIX F: PERMISSION FROM LEIC**



Life Esidimeni Proprietary Limited  
Intermediate care  
Ward 94, Lentegeur Hospital, 103 Highlands Drive,  
Mitchells Plain 7789  
PO Box 280, Mitchells Plain 7785  
Telephone: +27 21 370 9800  
Telefax: +27 21 370 9801  
www.lifeesidimeni.co.za

Re. Permission to Conduct Research with Life Esidimeni Intermediate Care

**Research Titles:**

The Adaptation and Contextualisation of the Bridges Stroke Self-Management Intervention for Patients Living with Stroke in the Western Cape, South Africa.

And

The effectiveness of the adapted Bridge's self-management programme in South African community-dwelling stroke survivors: A randomized controlled trial

**To whom it may concern**

Life Esidimeni Intermediate Care (LEIC) gives approval to the researchers of the above studies to conduct research with LEIC according to ethical practice and under the supervision of the Therapy Service Coordinator.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

8/9/17

Name: Charlene Jones

Designation: Hospital Manager



**LIFE ESIDIMENI INTERMEDIATE CARE**  
PO Box 280  
Mitchells Plain 7789  
Tel 021 370 9800  
Fax 021 370 9801

## APPENDIX G: CODEBOOK

<p>Interviewer: Okay auntie (“tannie”), so we said we are going to ask the questions again. Are you okay with that?</p> <p>Interviewee: Yes.</p> <p>Interviewer: Okay, so tell us again, how old are you?</p> <p>Interviewee: I am 46 and I am a woman.</p> <p>Interviewer: And when did you have the stroke?</p> <p>Interviewee: I had the stroke in 2013, on the 26th of May.</p> <p>Interviewer: Okay, good. So tell me about your life, after the stroke?</p> <p>Interviewee: After my stroke I went to live with my mother.</p> <p>Interviewer: Okay, and what else? So you had the stroke, and then where did you go? To the hospital?</p> <p>Interviewee: While I was having the stroke, the ambulance came to pick me up and took me to Worcester Hospital where I stayed for 2 weeks and after that I was transferred closer to my home in Caledon, where I was then immediately discharged.</p> <p>Interviewer: Did the doctors take good care of you?</p> <p>Interviewee: Yes, and I also received therapy there for one day before returning home.</p> <p>Interviewer: That was in Caledon?</p> <p>Interviewee: Yes, in Caledon.</p> <p>Interviewer: Okay, so you only received one day of therapy?</p> <p>Interviewee: Yes.</p> <p>Interviewer: And what did they show you?</p> <p>Interviewee: They showed me how to dress myself.</p> <p>Interviewer: And could you dress yourself by the time you left the hospital?</p> <p>Interviewee: No.</p> <p>Interviewer: Okay, so how did you help yourself to care of yourself again and dress yourself again? What did you do?</p>	<p>Time living in community</p> <p>Medical treatment received</p> <p>Rehabilitation received; intensity of therapy received</p> <p>Details of therapy</p>
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Translation –

Interviewee: In the hospital?

Interviewer: No, after the hospital.

Interviewee: After I left the hospital, my mother helped to bathe me and put on my clothes.

Interviewer: Okay, so did you experience any problems in taking care of yourself after you left the hospital following your stroke?

Interviewee: Yes, I couldn't take care of myself, that is why I had to go live with my mother who took care of me. She was very good to me and still is.

Interviewer: So what does your mother still do for you?

Interviewee: If I can't manage to put my clothes on right she helps me and if I've finished putting on my clothes she checks to see if I have done it correctly, and always helps to straighten out my clothes.

Interviewer: So you do it yourself and then your mother comes to help?

Interviewee: Yes.

Interviewer: So are there any other problems that you picked up with activities that you used to do before? Like you told me about finding it difficult to put on your clothes, are there any other activities that you had trouble with?

Interviewee: Yes, I had a big circle of friends before and now I actually have less friends, because my friends don't come to visit me like they used to because I can't do all the things I could before.

Interviewer: So give me an example, like what? What else could you do before that you can't do now?

Interviewee: I loved socialising with my friends, and dancing.

Interviewer: O, that's nice, and now, don't you dance anymore?

Interviewee: I dance, but now I have and dance to sit.

Interviewer: Why is that?

Help received; Caregiver info

Caregiver info; How the caregiver assisted

Caregiver info; How the caregiver assisted. Participant tried to help herself first

Socialisation

Challenges post stroke; Body awareness, participant realising her limitations post stroke

Socialisation

Modification of previous activity

<p><u>Translation –</u></p> <p>Interviewee: <b>Because I can't stand up properly anymore.</b></p> <p>Interviewer: Why can't you dance standing up? Because you can walk?</p> <p>Interviewee: Yes, but my <b>leg gets very tired.</b></p> <p>Interviewer: Okay, so you know your leg gets tired?</p> <p>Interviewee: Yes, and what I experienced, which isn't the case anymore, is <b>that my left foot starts shaking after I walk for a while.</b> Then <b>I have to put my foot down firmly and wait for the trembling to stop. But that doesn't happen so much anymore.</b></p> <p>Interviewer: So did someone tell you, or did you decide for yourself to rest when your leg starts shaking like that?</p> <p>Interviewee: <b>Someone told me, someone who had a stroke before me. I also saw her here today. She is from Voorstekraal.</b></p> <p>Interviewer: And other activities, like going to church. Did you have problems with that?</p> <p>Interviewee: Yes. Previously, it was a problem for me, not only because I tired easily, but also <b>because I did not have full control over my bladder.</b> So when I had to go to the toilet, I had to get there quickly, but now I would say that <b>I have much better control over my bladder.</b></p> <p>Interviewer: Okay. And is the church far from your house?</p> <p>Interviewee: No, the church is not far from my house.</p> <p>Interviewer: So, does it take long for you to walk from your house to the church?</p> <p>Interviewee: <b>It takes me about an hour to walk to church from my house.</b></p> <p>Interviewer: O, okay. And do you walk an hour without stopping?</p> <p>Interviewee: No, <b>I walk and then I rest when I get tired.</b> But the <b>walking downhill is fine</b>, it is more with the <b>uphill walking that I get very tired.</b></p>	<p>Challenge post stroke</p> <p>Body awareness, participant realising her limitations</p> <p>Body awareness</p> <p>Coping with challenges post stroke</p> <p>Advice from other stroke survivors</p> <p>Challenges post stroke</p> <p>Improved functioning post stroke</p> <p>Engaging in activities-Walking</p> <p>Modification of activity</p> <p>Engaging in activity-walking downhill</p> <p>Challenges post stroke</p>
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<p><u>Translation –</u></p> <p>Interviewee: <b>Walking back I don't really mind</b> how long it takes, or when I get back home, because I have <b>received (at the church) what I wanted to receive.</b></p> <p>Interviewer: So you don't know how long it takes to get back home from church?</p> <p>Interviewee: From the church to my house, it takes I don't know, it <b>takes longer because I also make it take longer by sitting and resting at certain points.</b></p> <p>Interviewer: So you know when your leg is going to get tired?</p> <p>Interviewee: I <b>don't always know when the leg is going to get tired, but I try to persevere</b> to a certain point and <b>tell myself that if I make it to that point, I am going to rest.</b></p> <p>Interviewer: Okay so you worked it out nicely! So before the stroke, did you work?</p> <p>Interviewee: Yes, <b>I worked on farms, and say, about ten minutes in a restaurant.</b></p> <p>Interviewer: (laughs) So before the stroke you worked on farms. And now, after the stroke?</p> <p>Interviewee: Now, after the <b>stroke I don't work anymore at all.</b></p> <p>Interviewer: Why?</p> <p>Interviewee: <b>Because I am cripple.</b></p> <p>Interviewer: Okay, so because you cannot stand for a long time? What are the reasons for you not working?</p> <p>Interviewee: <b>I can stand, but I cannot stand firmly on my left foot.</b></p> <p>Interviewer: O, okay.</p> <p>Interviewee: I <b>can stand</b> on it but it is quite unsteady, it can <b>easily give way underneath me when I walk, causing me to fall.</b></p> <p>Interviewer: So you spoke about dancing, how it was a hobby of yours but now you struggle with it. Are there any other hobbies that you had previously that are now difficult to do?</p>	<p>Engaging in activity-walking; Attitude</p> <p>Religion</p> <p>How participant engaging with hobbies</p> <p>Uncertainty</p> <p>Participant not giving up</p> <p>Self-motivation</p> <p>Employment</p> <p>Employment</p> <p>Attitude- Negative self-talk</p> <p>Functioning post stroke</p> <p>Functioning</p> <p>Concerns post stroke</p> <p>Fear of falling</p>
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<p><u>Translation –</u></p> <p>Interviewee: <b>Cooking.</b></p> <p>Interviewer: So you liked to cook before, and now?</p> <p>Interviewee: Now my mother does the cooking.</p> <p>Interviewer: And don't you help your mother to prepare the food?</p> <p>Interviewee: Yes, <b>sometimes I help to peel the potatoes, with my one hand like they taught me.</b></p> <p>Interviewer: Who taught you that?</p> <p>Interviewee: <b>Physiotherapy people.</b> And I think it was you come to think about it, wasn't it you who taught me that (at the hospital)?</p> <p>Interviewer: (laughs). So you do help your mother with the cooking?</p> <p>Interviewee: <b>Yes.</b></p> <p>Interviewer: Okay, so tell me about the challenges you have in your environment after the stroke?</p> <p>Interviewee: After the stroke I always wondered how it looked outside, <b>because I couldn't get up to look myself.</b> And where I lay in my bed, it was too low to see out onto the street in front of the house, to see what was going on. It was <b>four or five</b> months before I could go outside on the porch, and then only did I actually realise what a beautiful view it was.</p> <p>Interviewer: So you have a porch at home?</p> <p>Interviewee: Yes, a high porch.</p> <p>Interviewer: And are there any steps?</p> <p>Interviewee: Yes, <b>there are steps which were also very difficult</b> for me <b>because I was very scared of falling</b> But <b>eventually I got used to climbing the steps with my crutch,</b> and even when <b>I had the crutch I would use it just in case I fell so there</b> was someone to help me.</p> <p>Interviewer: Okay, and in the house, are the floors slippery?</p> <p>Interviewee: <b>No, the floors are not slippery because we don't have tiles or things like that.</b></p> <p>Interviewer: Okay, and are the roads tarred there where you live?</p>	<p>Engaging in activities-cooking</p> <p>Modification of previous learnt activity; Therapy received</p> <p>Therapy received</p> <p>Engaging in activities-cooking</p> <p>Challenges post stroke</p> <p>Time period</p> <p>Challenges post stroke; external environment</p> <p>Concerns post stroke</p> <p>Modification of activity</p> <p>Fear of falling post stroke</p> <p>Home environment</p>
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Translation –

Interviewee: No, there are gravel roads and cobble roads. And the roads are very uneven, but that actually helps me because it is like an exercise for me.

Interviewer: O, well done! So who told you to walk on the cobble road for exercise? Did you decide yourself?

Interviewee: Even if someone told me I shouldn't walk on the cobble road, I had no choice because it is the only road there is.

Interviewer: And the social environment? How did you find that?

Interviewee: Social?

Interviewer: Yes, like the relationships you have with you mother, family, friends? Did they look after you and care about you more after your stroke?

Interviewee: Like my parents?

Interviewer: Yes, or the family?

Interviewee: Yes, actually they looked after me throughout the years, we are a very close-knit family. After my father's passing, it was even more so, because before he died he said we should be obedient and look after my mother.

Interviewer: And now, do they look after you?

Interviewee: Yes, now they look after me! (laughs)

Interviewer: So they help you, they work nicely with you?

Interviewee: Yes, I got panic attacks about a year after the stroke. It upset my brother so much he would cry, because he thought I could have another stroke. But it turned out it was panic attacks, there were a lot of things in my subconscious from my past that resurfaced. Like the boyfriend I had that I told you about. He drank a lot, he was twelve years younger than me, and when he drank he was very mean to me, and I never spoke to anyone about it because I didn't want people to know what kind of person he really was in the home.

External environment

External environment- Exercise to engage in environment

External environment-participant saw no other alternative.  
Participants' internal factors

Social- family life; Family support

Social- family dynamic

Concerns post stroke

Social- partner/spousal dynamic;  
lack of spousal support



Translation –

Interviewer: So that caused you a lot of stress?

Interviewee: Yes, I actually tried to protect him.

Interviewer: Okay, but then you got sick?

Interviewee: Yes, that's it.

Interviewer: And the people walking in the street, do they look at you when you walk past them?

Interviewee: Yes, you know it is human nature to be curious. There will always be those people who are curious, but I actually enjoy all the questions they ask me. Like, are you alright? And, you should try this or that (remedy).

Interviewer: And before the stroke, did they greet you nicely?

Interviewee: Yes, but you know I was always a very friendly person who liked to joke with my friends and greet everyone and make them laugh and feel good.

Interviewer: And after the stroke?

Interviewee: After the stroke they still visited me, but after a while they started to visit less and less. Now they almost never visit?

Interviewer: But why is that?

Interviewee: Because now I visit them, because I want to walk!

Interviewer: That's good, well done! So the relationships did not really change.

Interviewee: No, the relationships did not really change. Because I told them you don't have to come to me anymore, I will come and surprize you. One woman told me, Manda, did you really have a stroke, because you would never say I had a stroke. But I spoke with difficulty, my tongue would often drag the words.

Interviewer: So did you do something to improve it? Did someone help you?

Interviewee: My mother heard from someone that I should eat mebos sweets and so I did that, and you know eating is also a good exercise (for speech).

Social life

Self- Participants demeanour;  
internal factors

Social life-friends and the support  
she received

Self-motivation- Participants internal  
factors

Internal factors-  
relationship/friendship building.  
Participant not allowing the stroke to  
get the better of her

Challenges post stroke

Advice from others, sharing  
knowledge.

Engaging with shared knowledge

Knowledge, Exercise to promote  
recovery post stroke

Translation –

Interviewer: And did you do anything else?

Interviewee: I massaged my weak side with ointment, because the physiotherapists told me that I should remember to do that so my weak side knows it is still part of my body.

Interviewer: So you still do that?

Interviewee: I do, because I still love it (the weak part). Even if it doesn't get better, I know it will get better one day in heaven. I am satisfied.

Interviewer: So how else did you help yourself to improve your functions?

Interviewee: I touched the weak part a lot, spoke, walked slowly. Even if I could walk fast I didn't because I was afraid of falling.

Interviewer: Okay, and you spoke about walking on the cobble road for exercise for your body. Did you do any other exercise to help yourself?

Interviewee: Yes, with my hand.

Interviewer: What did you do with your hand?

Interviewee: Should I demonstrate?

Interviewer: You can just explain.

Interviewee I opened and closed my hand with the help of my right hand. And lifted my elbow. All with the help of my right hand I stimulated my left side, not with the help of others. And lifting my leg and bending my knee.

Interviewer: That's good. And did you ask for help when you needed it? Like you mentioned when you tried to climb up to the porch.

Interviewee: Yes. Mind over Matter has a combi which transports us in the mornings and in the afternoons back home. And when I get home, they help me out of the taxi and then my mother comes to get me at the gate. And she would help me get back into the house. Later I told my mother I wanted to try to walk by myself, she could just walk beside me and later it wasn't even necessary for her to come out anymore when the taxi came, because now I walk by myself.

Advice from health care professionals, engaging with shared information

Therapy received

Religion- Spirituality

Exercise to promote recovery post stroke

Fear of falling post stroke

Exercise to promote recovery post stroke

Exercise- retraining of the affected side

Social- engaging with community initiatives

Help received

Caregiver

Modification of the manner she would previously use to get into the house

Self- awareness and motivations

Functioning post stroke

Translation –

Interviewee: And if the taxi stands a certain way, I can even get into **the taxi by myself now.**

Interviewer: So do you ask for help, or do you wait for someone to offer help?

Interviewee: I don't wait for someone, **I first see if I can do it myself**, and if I can't do it, then I will ask for help.

Interviewer: Good. And if you are at home, do you also ask for help?

Interviewee: I **ask for help when I see I need it**, and sometimes, when I am angry, I don't want to be helped at all. (laughter) Seems to me those are the times when I get things right so quickly!

Interviewer: Yes, but anger is not good for the stress, right?

Interviewee: No, it is not good.

Interviewer: So actually you are saying that you plan your movements. Like when you see the combi is not parked near enough, you plan for that?

Interviewee: Yes, yes.

Interviewer: So are there any other times where you plan?

Interviewee **Yes, when I sit, I always want to sit at the end, I don't want to sit between people.**

Interviewer: Why?

Interviewee: **So that when I want to move, I can do so easily, I don't want to be stuck between them.**

Interviewer: So are there any other things that you plan for?

Interviewee: When I go **to visit somewhere**, I also like to **plan ahead so I can pack all my things that I might need.**

Interviewer: So do you do that by yourself or does someone help you?

Interviewee: **I do it myself.**

Interviewer: Okay, thank you very much, that was a very good interview.

Interviewee: Thank you Miss Janine.

Modification of activity

Self

Asking for help

Planning ahead

Modification of activity

Socialisation

Planning

**APPENDIX H: REFLECTIVE POEM**



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**REFLECTIVE POEM**

**Project Title: Self-management strategies employed by stroke survivors in the Western  
Cape, South Africa**

I see

I see myself with arms open

W I D E

absorbing all of my senses

Why, oh why, is my energy depleted?

Why, oh why, is my spirit d r a I n e d...



The stench of urea

L i n g e r s...

As I enter,

you apologise

I give a weak smile

I see your walking frame

F O L D E D

Why not ready to use?

Like a ready to eat salad from "Aunty Woolies"?

I hear you... The air is

P I E R C E D

By silence...

You sigh.

Your expression is deafening

as you relive the day after the day your life was changed forever.

Your lived experiences my olfactory system is eating up. It tastes:

S C R U M D I D D L Y Y M P T I O U S !

How you have overcome your challenges

has me salivating.

Your story: so raw; so pure.

I see the lines of frustration

C a r v e d

On your face from hours of toiling to relieve your spasticity.

I wonder if you can perceive that I've noticed.

No words are uttered though.

Your spasticity feels

T A U N T

under my hands that are meant to heal.

You resist, unbeknownst to you

Somehow the watts terminate in your ® UL

There's light in your eyes as your arm



"Feels like it's a part of your body- again"

Hemi-neglect a thing of the past!

It's been 6 months later and I can still taste the

U N E A S E.

My bed is warm and my mind is full.

My being succumbs to the array of emotions.

I see everything like it was yesterday... when I said I'll never forget, what I meant is, I am forever changed. (For the)

B E T T E R

*J.L Smith*



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