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**Stroke patients' perspective of community reintegration after receiving
Occupational Therapy intervention at a District Hospital in the Western
Cape, South Africa**

UNIVERSITY OF THE WESTERN CAPE

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7 September 2022

Declaration

I declare that *Stroke patients' perspective of community reintegration after receiving Occupational Therapy intervention at a District Hospital in the Western Cape, South Africa* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Name: Sunel-Marie Van der Westhuizen

Date: 7 September 2022

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Abstract

Strokes have a major impact on disability globally. According to literature, stroke patients may find it difficult to resume activities and roles post stroke as well as experience limited community reintegration due to lack of services and knowledge within South Africa. The aim of the study was to explore and describe stroke patients' experiences of community reintegration after receiving occupational therapy intervention. The study followed a qualitative research approach with an exploratory descriptive design. Purposive sampling was used to recruit participants. Ten participants and two key informants were selected to participate in the study. The selected ten participants have already reintegrated back into their communities, while the two key informants work at a district hospital in the Western Cape as either an occupational therapist or a physiotherapist. Data was collected using semi-structured interviews with each of the ten participants and the two key informants. All transcribed data was analysed thematically and the following three themes emerged, namely: (i) stroke survivors' challenges related to participation in functional tasks or occupations, (ii) stroke survivors' facilitators related to participation in functional tasks or occupations, and (iii) adaptation strategies utilised by stroke survivors to reintegrate back home and into the community. The results indicated that stroke survivors experience barriers at environmental and resource levels; however, facilitators included supportive systems that enhanced function where the stroke survivors were able to use the facilitators as an adaptation strategy to improve reintegration into the community. It is therefore recommended that service providers recognise the challenges experienced by the stroke survivors to provide reasonable intervention changes or revise intervention programmes in order to enhance post stroke integration back into the community.

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Abbreviations

ADLs: Activities of daily living

OAM: Occupational Adaptation Model

IADLs: Instrumental activities of daily living

CHCs: Community Health Centres

CSP: Comprehensive Service Plan

CVA: Cerebrovascular Accident

WCRC: Western Cape Rehabilitation Centre

WHO: World Health Organisation

OT: Occupational Therapist

MDT: Multidisciplinary Team

HBC: Home Based Care



Key Words and Definitions

Stroke: An acute neurological dysfunction of vascular origin with sudden (within seconds) or at least rapid (within hours) occurrence of symptoms and signs corresponding to the involvement of focal areas in the brain (World Health Organization, 1989)

Rehabilitation: A process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimum physical, psychological and social function (Royal College of Physicians and British Society of Rehabilitation Medicine, 2003)

Outcomes: Results that occur after an intervention

Participation: Involvement in a life situation (World Health Organization, 2002)

Activity limitations: Difficulties an individual may have in executing activities (World Health Organization, 2002)

Participation restriction: Problems an individual may experience in involvement in life situations (World Health Organization, 2002)

Community reintegration: involvement in re-establishing or developing new or previously existing roles and relationships (Wilson et al., 2005)

Basic Activities of Daily Living: Tasks that include self-care, functional mobility, sexual activity and sleep/rest (Pendleton & Schultz-Krohn, 2006)

Instrumental Activities of Daily Living: Tasks that include community device use, health management and maintenance, financial management, meal preparation and clean-up and community mobility (Pendleton & Schultz-Krohn, 2006)

Multi-disciplinary team: Group of specialists whom determine the diagnosis and treatment plan to achieve interventions but stay within the scope of practice (World Health Organization, 2018)

Inter-disciplinary team: Analyses and synthesize links between disciplines and teams work interdependently to achieve a treatment plan (Cooper & Fishman, 2003)



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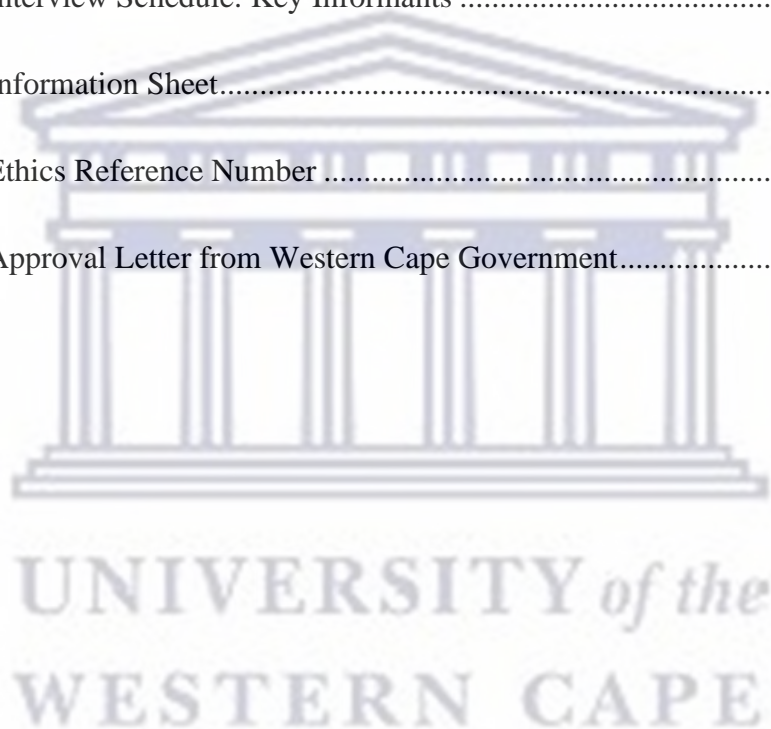
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CHAPTER ONE

Overview of the Study

1.1 Background

This study served as an investigation to stroke patients' own perspectives of community reintegration post occupational therapy intervention at a district hospital within the Western Cape. During the course of my work as an occupational therapist it came to my attention that stroke patients at a district hospital experienced limitations in community reintegration. Family members seemed to be overwhelmed by their new normal and that some patients were unable to attend follow-up appointments once they were discharged from the inpatient facility. While a stroke guideline was developed within an South African context (Bryer et al., 2010). There is very little information on the implementation, monitoring and assessment of rehabilitation services in Africa (Tawa et al., 2021). As an occupational therapist, the researcher aimed in this study to contribute a deeper understanding of what stroke patients experience in order to develop and implement a client-centred approach to community reintegration.

1.2 Introduction

Stroke is defined by the World Health Organisation (WHO) as “an acute neurological dysfunction of vascular origin with sudden (within seconds) or at least rapid (within hours) occurrence of symptoms and signs corresponding to the involvement of focal areas in the brain” (World Health Organization, 1989, p.1412). It is well known that the functional effects of a stroke have a devastating effect on communities. According to Statistics South Africa (2016) stroke is the third leading cause of death in South Africa, while the World Stroke Organisation recorded that 63% of healthy life lost due to stroke-related death and disability affects people under the age of 70 years (Lindsay et al., 2019).

The lives of stroke survivors can drastically be challenged and daily tasks may become more difficult to complete independently or to participate in compared to their premorbid level of function (Hartman-Maeir et al., 2007; Wasserman et al., 2009).

A qualitative study done by Kloppers et al. (2016), confirmed the benefits and satisfaction of participating in a rehabilitation programme, indicating that it had a drastic emotional and physical advantage in improving the daily life activities of stroke survivors within their own communities. The findings of the study also emphasised the value and advantages of educating fellow community members regarding their diagnosis, body functions and methods for improving activities of daily living (ADLs), functioning and independence.

However, according to a study done in rural KwaZulu-Natal, stroke patients were discharged on average six days after hospitalisation, and two-thirds received no stroke education prior to discharge from hospital as there were no stroke rehabilitation facilities (Wasserman et al., 2009). The findings of the study conducted by Wasserman et al. (2009) emphasised that community education and services are required to facilitate the successful community reintegration by clients diagnosed with a stroke.

1.3 Problem Statement

According to the World Federation of Occupational Therapy (WFOT) (2020), occupational therapy refers to a client-centred health profession that improves health and wellbeing through occupations. Occupational therapy as a profession assists people to participate in their activities of daily life. Occupational therapists base their focus of therapy on improving peoples abilities to engage in occupations that are meaningful to the person they are working with by modifying the occupation or the environment (World Federation of Occupational Therapy, 2020).

Occupational therapy services are rendered at various public hospitals within the Western Cape. The researcher showed through clinical observation that stroke patients and their families experience a lack of knowledge and anxiety with regards to insight into community reintegration once being discharged from a district hospital.

Hartman-Maeir et al. (2007) found that one year post stroke, patients experienced more dependence on instrumental activities of daily living (IADLs) compared to basic activities of daily living (BADLs). BADLs can be define as “tasks that include self-care, functional mobility, sexual activity and sleep/rest” while IADLs can be defined as “tasks that include community device use, health management and maintenance, financial management, meal preparation and clean-up and community mobility” (Pendleton & Schultz-Krohn, 2006, p. 147). A study conducted in Johannesburg, South Africa, found that community reintegration after a stroke was limited and that patients experienced limitations in the areas of extended family responsibilities and work. It further stated that only 27.8% of the stroke survivors experience full community reintegration after receiving inpatient rehabilitation services (Kusambiza-Kiingi et al., 2017). It is evident that stroke patients have difficulty reintegrating back into their communities after being discharged from hospital. It could be argued that understanding a patient’s perspective and challenges after being discharged from a district hospital may guide occupational therapists and service providers to follow a more client-centred approach and address limitations when treating stroke survivors in district hospitals, essentially leading to improved functionality and community reintegration.

1.4 Research Questions

What are the experiences of stroke survivors about community reintegration after receiving inpatient occupational therapy intervention at a district hospital in the Western Cape?

1.5 Research Aim and Objectives

The aim of the study is to explore and describe the perspectives and experiences of stroke survivors' community reintegration after receiving inpatient occupational therapy intervention at a district hospital in the Western Cape.

The objectives of the study are as follows:

1. To explore the stroke survivors' perspectives and experiences of barriers when reintegrating into the community after completing inpatient occupational therapy intervention
2. To explore the stroke survivors' perspectives and experiences of facilitators when reintegrating into the community after completing inpatient occupational therapy intervention
3. To explore the stroke survivors' perspectives and experiences of adaptive strategies used when reintegrating into their occupational roles in the community
4. To explore the strategies to enhance the ability of stroke survivors to reintegrate into the community

1.6 Outline of Thesis

The thesis comprises the following chapters:

Chapter 1 provides the background, problem statement, research question, aims and objectives of the study.

Chapter 2 presents a detailed presentation of the literature review including the study's theoretical framework.

Chapter 3 describes the methodology utilised in the study.

Chapter 4 reports on the findings of the study.

Chapter 5 presents the discussion of the findings from chapter 4. The aim and objectives are addressed in relation to previous literature.

Chapter 6 involves the conclusions that emerged as well as a discussion on the limitations and recommendations.



CHAPTER TWO

Literature Review and Theoretical Framework

2.1 Introduction

This chapter describes literature of stroke rehabilitation globally as well as within a South African context. Furthermore, the community reintegration of stroke patients after having a stroke within a South African setting is highlighted. Lastly, this chapter describes the theoretical framework within this study, namely the Occupational Adaptation Model (OAM) (Schkade & Schultz, 1992).

2.2 Stroke

Stroke is characterised as a neurological disturbance of an acute localised injury of the central nervous system from a vascular origin. Globally, stroke is one of the world's major causes of death and disabilities (Sacco et al., 2013).

2.2.1 Types of strokes

A stroke can be divided into the following two main types namely: (i) an ischaemic stroke or (ii) a haemorrhagic stroke (Gomes & Wachsmann, 2013). The *ischaemic stroke* occurs as a result of a blockage of the cerebral artery of either an embolus or thrombus, while a *haemorrhagic stroke* is caused by a weakened cerebral artery that ruptured (Mackay & Mensah, 2004). Most strokes are ischaemic strokes (85%) while cerebral haemorrhage strokes (15%) are less common (Bryer et al., 2010).

2.2.2 Risk factors of a stroke

According to Bryer et al. (2010) the most common risk factors for a stroke include the following that frequently coexist:

- High blood pressure; smoking or tobacco use; increase body mass index (BMI); physical inactivity; diabetes mellitus; increased amount of alcohol and drug consumption; HIV/AIDS, and current heart disease.

Hypertension is considered as one of the main risk factors for a stroke within the South African population (The heart and stroke foundation South Africa, 2016).

2.2.3 Effects of a stroke

The brain controls complexed body functions. With various arteries supplying the brain, the CVA's outcome depends on the supplying artery that was involved. The client's limitations experienced in occupational performance depends on the different anatomical structures involved. The effects of a stroke may include but are not limited to hemiplegia; paralysis, language and swallowing difficulties, memory loss, visual problems and behavioural changes (Gillen, 2006).

2.3 Burden of Stroke

The burden of stroke refers to a stroke population's incidence, prevalence and mortality (Fisher et al., 2017). Studies on epidemiology, incidence and prevalence related to stroke are limited in developing countries due to the lack of financial resources and the expertise for proper execution (Fisher et al., 2017). Stroke is ranked ninth in terms of one of the major causes of disability in South Africa. Strokes have a major financial impact on the patient and their family members due to the fact that most stroke survivors require hospitalisation, rehabilitation input or additional homecare post stroke. (Bryer et al., 2010).

2.3.1 Stroke incidence

According to the Centers for Disease Control and Prevention (2020), incidence can be defined as the occurrence of newly reported cases of disease or injury within a population over a certain

time period. Stroke incidence varies according to age, gender, ethnicity, and geographical location. According to a study by Johnson et al. (2016), 70% of strokes and 87% of stroke-related deaths and disabilities globally, occur in low- and middle-income countries, and statistics in these countries have doubled over the past four decades. In the same study Johnson et al. (2016) state that stroke incidence has decreased by 42% in high-income countries. The incidence of stroke rapidly increases with age, and is said to double for each decade after the age of 55. Strokes in children are substantially lower when compared to those in adults (Ovbiagele & Nguyen-Huynh, 2011). Ovbiagele and Nguyen-Huynh (2011) further state that individuals of Asian, African and Latin American origin have an increased risk of stroke compared to persons from European origin. Significant disparities have been found between men and women with stroke. According to Johnson et al. (2016) men consistently have a greater risk of a stroke compared to that of women.

2.3.2 Stroke prevalence

Prevalence can be defined as the number of persons in a population who have a specific disease at a specific time or over a specific period of time (Centers for Disease Control and Prevention, 2020). Globally it is estimated that in 2005, 16 million people suffered their first stroke with a prevalence of 62 million people surviving a stroke (Mukherjee & Patil, 2011). More than 80 million people are currently living with a stroke or have experienced a stroke in their lifetime while 60% are under the age of 70 years (World Stroke Organization, 2019). Limited data is available on the prevalence of stroke in South Africa. The South African Stroke Prevention Initiative (2004) published the first ever stroke prevalence study in South Africa. The study recorded a crude prevalence rate of 300 per 100 000 of the population, with a 95% confidence interval. A higher prevalence rate was also recorded for women compared to men (South African Stroke Prevention Initiative, 2004).

2.3.3 Stroke mortality

Stroke is the second most common cause of death, and the third most common cause of disability worldwide affecting 25.7 million people (Fisher et al., 2017). Five and a half million people die of strokes every year while 39% of those people are under the age of 70 (World Stroke Organization, 2019). According to Statistics South Africa (2015) a stroke is one of the highest causes of death within South Africa with HIV as the leading cause of death. Cardiovascular disease (including heart disease and strokes) is the cause of 17.3% of deaths in South Africa, and it is estimated that about 215 people die from cardiovascular diseases daily in South Africa (Statistics South Africa, 2015).

2.4 The Rehabilitation Process

Stroke survivors may experience a decrease in functionality as well as limited community reintegration (Kloppers et al., 2016). According to a study done in Canada, stroke rehabilitation has been found to be most effective when rehabilitation is started in the first week post stroke (Teasell et al., 2016). Recovery reaches a peak within the first three months post stroke and, while the recovery rate will be slow for a couple of months thereafter, recovery is still possible months and even years after the stroke (Teasell et al., 2016). Improved functionality has been found in patients with stroke who were admitted to a stroke unit compared to patients who received treatment in a general ward (Stroke Unit Trialists' Collaboration, 2013).

Rehabilitation services within developed countries such as the United States can be broad and vary according to the care setting. These variables include the duration, intensity, and type of interventions as well as the involvement of the rehabilitation team members (Winstein et al., 2016). A study in Gauteng, South Africa, aimed to establish the functional independence of stroke patients at discharge and six weeks post discharge in order to establish if the length of

hospital stay affects the functional outcome of stroke patients (Mamabolo et al., 2009). It was found that that 93% of stroke patients were more functionally independent at six weeks post discharge compared to 47% at discharge. It was confirmed that being an inpatient for more than six weeks increased the probability of improved independence in function prior to being discharged home. This may be due to spontaneous recovery or the person and his caregivers' ability to adapt to their new circumstances. As mentioned earlier, the Western Cape has limited inpatient rehabilitation services available, and that patients are discharged back into the community with limited information on the availability of further rehabilitation services (Kloppers et al., 2016). According to the knowledge of the researcher, stroke patients at a district hospital will receive multidisciplinary stroke rehabilitation. The inpatient rehabilitation in the acute phase varies from one to three weeks and patients are discharged back into the community or transferred to a stroke rehabilitation unit; however, as mentioned earlier, the stroke rehabilitation units have limited availability to admit all potential stroke survivors for further rehabilitation.

A study done within the Western Cape, South Africa aimed to determine the activity limitations, participation restrictions as well as the impact on the quality of health of stroke survivors six months after having been discharged from an intensive inpatient rehabilitation programme. The study showed that patients received little healthcare input after discharge and that 10% had no further contact with healthcare services after having been discharged from hospital (Rouillard et al., 2012). Thus, patients and caregivers may find it challenging to cope with adapted life roles and functions once discharged from district hospitals. Patients and caregivers now have to adapt to new roles and adapted functioning due to physical and psychological limitations.

2.4.1 Stroke rehabilitation

Stroke rehabilitation can be defined as a “goal-orientated process which attempts to improve a stroke patient’s maximal functionality in terms of physical, cognitive and language disabilities” (Bryer et al., 2010, p.775). Bryer et al. (2010) further state that the stroke rehabilitation process should be executed as an interdisciplinary approach by a specialist team who have experience and understanding of stroke rehabilitation. Stroke rehabilitation involves a four-step process. This process comprises the following: a) assessment to identify a client’s needs; b) goal setting for improvement; c) intervention to reach the set goals; and d) reassessment to assess progress according to agreed goals (Langhorne et al., 2011). Stroke rehabilitation can be provided in different settings. These settings will depend on various factors; however, the two main settings include inpatient rehabilitation and outpatient rehabilitation that also includes a home-visit rehabilitation.

2.4.2 Inpatient rehabilitation

Inpatient rehabilitation refers to organised inpatient care (stroke unit), where care was coordinated by a multidisciplinary team (Stroke Unit Trialists’ Collaboration, 2013). According to a randomised controlled trial comparing organised inpatient care to alternative forms of care for people suffering a stroke found that, stroke survivors are more likely to survive, return home and gain more independence when they receive organised inpatient care (Stroke Unit Trialists’ Collaboration, 2013).

2.4.3 Outpatient rehabilitation

The concept of continuation of therapy at home is widely accepted by patients and their families. Patients feel that they will be able to continue rehabilitation on an outpatient basis rather than having an extended hospital stay. The concept of Early Supported Discharge (ESD) developed from this. ESD service refers to a service that aims for an early hospital discharge to continue multidisciplinary rehabilitation at home (Langhorne et al., 2011). According to a

study by Langhorne et al. (2011) the concept of ESD seems to be most effective with patients who experience mild to moderate disability. Langhorne also states that therapy-based rehabilitation at home for one year improved the functional outcome of stroke patients.

2.4.4 Stroke rehabilitation within a South African context

A clinical practice guideline was developed for recommendations into local rehabilitation practice (Grimmer et al., 2019). According to the study the previous clinical practice guideline was outdated and had a more medical approach with only a few rehabilitation guidelines. The steps to adopt in South African rehabilitation within the next six months included:

- Rehabilitation should commence in the acute setting
- A standardised assessment for dysphasia should be applied
- Education to healthcare staff on adverse events should be available
- All patients should be mobilised as soon as possible
- Patients with mild and moderate stroke should have short but more frequent sessions
- Recommendation against using splints or prolonged positioning
- Comprehensive assessment of rehabilitation should include
- Strong evidence that the multidisciplinary rehabilitation team operate most effectively when sharing assessments and rehab tasks, and communicate findings verbally or written
- Treatment decisions should be documented
- Progression of rehab programmes should be documented
- Assistive and adaptive equipment should be used for safety and function only
- Discharge planning should include all team members and family
- Discharge planning should articulate patient and family circumstances

- Every member of the rehab team should take responsibility for planning and monitoring the continuation of care
- Patient progress should be documented and shared at discharge planning meetings
- One member of the rehab team should take over all responsibility of discharge planning to ensure continuity
- Longer term care for stroke survivors should reflect their goals and circumstances

Another guideline to manage stroke-related incidents was developed locally (Bryer et al., 2010). The objective was to update the 2000 version with new evidence within a South African context.

According to the guideline, Goals of Stroke Rehabilitation, the following steps should be taken:

- Enable patients to resume their pre-morbid function, alternatively strategies should be considered
- Skills retraining may be considered if unable to resume work
- Reducing the burden of care for families should be considered for patients with permanent disabilities
- Training of caregivers should be addressed by the rehabilitation team

An important characteristic of the stroke unit model of care is that rehabilitation should be delivered by a multidisciplinary team with regular communication to work towards common aims and objectives for the patient. Patients should be assessed fully within 24 hours of onset of the stroke by each team member. Communication with both the patient and their family is of vital importance, and a formalised family meeting should be held ideally within the first week of therapy. The aim of these meetings should focus on education and the anticipated outcomes.

Discharge planning is an integral part of rehabilitation. In urban settings, inpatient facilities should allow patients to return home prior to being discharged, in order for families and the patient to assess any difficulties they may have experienced within their home environment and for these issues to be addressed by the team before a final discharge. Even in rural areas patients should have the same opportunities as in urban areas. Post discharge rehabilitation is of vital importance where necessary, and appropriate referrals for therapy should be made prior to being discharged.

The focus of occupational therapy intervention should include resumption of daily activities like grooming, toileting, washing, shaving, dressing, and eating. Other issues like neglect, and perceptual and visual difficulties should also be addressed. Occupational therapists should identify and issue assistive devices like wheelchairs, walking aids and bath and shower aids.

2.5 Community Reintegration

Community reintegration is an important outcome of rehabilitation. Stroke survivors experience difficulty in executing different tasks and activities in their life after being discharged (Kersten et al., 2002). The reintegration to normal living index (RNLI) identifies 11 statements used to describe the degree to which people return to normal life (Wood-Dauphinee, SL et al., 1988). Ten domains of reintegration to normal living have been identified by Obembe et al. (2002), these include indoor mobility, community mobility, distance mobility, self-care, daily activities, recreation activities, social activities, family role, personal relationships and general coping skills. Accessibility for persons with disabilities in South Africa, India, Malawi, Mozambique and Mexico was assessed by (Venter et al., 2002). The report shows that smaller minibusses provided improved accessibility compared to larger

busses as they were smaller in size and more readily available. Furthermore, it was found that the driving behaviour of drivers of public transport constitute major barriers for people with disabilities. In Blantyre, Malawi, bus drivers do not provide sufficient time for people to board or alight safely from the busses and lack awareness and training in assisting people with disabilities.

Some stroke survivors experience limitations in returning to their previous economic activity. A study by Koch et al. (2005) reports that most stroke survivors are unable to return to their previous level of employment. The study further describes the emotional problems that arise when stroke survivors experience failure to perform these tasks, leading to the inability to participate in economic activities. Pre-stroke roles as “bread-winners” may be impacted by the inability to return to work (Obembe et al., 2002). According to Rudman et al. (2006) families or caregivers of stroke survivors may also experience economic restrictions due to the fact that they feel that the stroke survivor may experience an injury when they leave them, therefore affecting work-related activities. According to a study by Govender et al. (2019) stroke survivors were unable to return to work and those who did experienced a reduced number of tasks from their previous job functions.

In the United States the effects of stroke disability on spousal and caregivers was studied and found that women experienced particular problems and limitations to complete IADL activities especially household tasks like cooking and childcare (Blonder et al., 2007). A study in New Zealand compared the health related quality of life of long term stroke survivors and found that some stroke survivors also had problems with the ability to walk outside (Hackett et al., 2000). Not only does the stroke affect them physically to carry out their daily tasks but while stroke survivors lose the ability to perform these tasks it also has an emotional impact on them as they feel that they are failing to perform tasks like driving, housework, and the ability to manage their finances (Koch et al., 2005).

Stroke survivors also experienced stigmatisation and social isolation when other people in their community thought they were cursed and this directly influenced community reintegration as stroke survivors did not resume their pre-morbid activities within their community (Govender et al., 2019). As mentioned earlier, South Africa has stroke management and rehabilitation guidelines available, however these guidelines are not always implemented (Bryer et al., 2010). According to Mapipa et al. (2016) numerous reasons for poor adherence to continue therapy were found. The main reasons identified by patients for poor adherence were the unavailability of transport, the poor services they received at primary health clinics, limited therapy sessions (one session every 14 days), untreated depression, and limited insight into their condition due to poor education. A study done in KwaZulu-Natal explored the experiences and the factors that restricted community reintegration of stroke survivors in a peri-urban area. The findings revealed key limitations which included poor education on access to available rehabilitation services, poor carer or family training and the need for inpatient rehabilitation services (Govender et al., 2019). Some stroke survivors suggested that they were not prepared to return home as they did not receive sufficient advice or family training, while they also experienced a lack of referral following discharge (Govender et al., 2019). According to a study done in the Western Cape it was found that patients who received therapy at a specialised inpatient rehabilitation centre still experienced poor community reintegration (Gretschel et al., 2017). This may be due to the fact that rehabilitation within the Western Cape has been limited as frequency and length of treatment sessions were constrained due to a lack of staff (Kumurenzi et al., 2015). Therefore, it is of great importance to explore the reasons for poor community reintegration from stroke-survivors' perspectives and to identify the key barriers and limitations they experience in order to improve their functional outcomes.

2.6 Impact of COVID-19 Pandemic on Stroke Rehabilitation

In December 2019 the first Coronavirus (COVID-19) case was reported in Wuhan, Hubei Province in China and quickly spread to the rest of the world in 2020 (Stoecklin et al., 2020). Drastic measures were subsequently applied as individuals around the world had to adhere to social distancing, the wearing of face masks, and various methods of lockdown protocols adopted to fight the spread of COVID-19. Worldwide the COVID-19 pandemic has impacted morbidity and mortality rates of stroke victims. According to a study that was conducted in Germany, a significantly decreased number of strokes was reported during the COVID-19 pandemic (Hoyer et al., 2020). Furthermore, decreased hospital admissions for strokes were reported. This phenomenon could be due to the fact that individuals feared the high COVID-19 infection rates at hospitals (Fuentes et al., 2020). Further investigation and research is required to evaluate the impact and long-term effects on stroke rehabilitation outcomes (D'Anna et al., 2021).

2.7 Theoretical Framework

The Occupational Adaptation Model (OAM) (Schkade & Schultz, 1992) is being utilised as the theoretical framework within the current study. The model suggests that mastery is more than the capability to execute a task. It is the impression experience of a client as an occupational being (Schkade & Schultz, 1992). The process is based on the internal interaction between three elements of occupational adaptation: the person, the environment, and their interaction with one another. According to the model, the change in one element will directly influence the other elements. The primary goal of the occupational adaptation process is to achieve mastery over the environment. The desire, demand and press for mastery are constantly present within an occupational environment. The elements or components of occupational adaptation can be described as: *a) the person*, which focuses on the internal factors of the

person with a constant desire for mastery. The person is made up of unique systems: sensorimotor, cognitive, and psychosocial systems; *b) occupational environment*, which represents the external factors of the occupational adaptation process that affects the person. The process in the occupational environment begins with a constant demand for mastery. This context comprises the physical, social, and cultural influences; *c) interaction*, where the press for mastery is a constant factor that yields the occupational challenge. Expectations of occupational roles and the occupational environment intersect in response to the presented occupational challenge and then a demand for adaptation occurs; and *d) adaptive response* is made up of three subprocesses that are internal to the person. The three subprocesses are the generation subprocess, the evaluation subprocess, and the integration subprocess and these explain the adaptive response activated by the person in response to an occupational challenge. Through the subprocesses, the person plans the adaptive response, evaluates the outcome, and integrates the evaluation as adaptation. The inability to generate an appropriate adaptive response as a result of personal factors or environmental factors could lead to dysfunction. An imbalance between the desire and demand for mastery could lead to inability to adapt to an occupational challenge, namely, dysfunction. Dysfunction also occurs when challenges exceed the person's capacity to adapt.

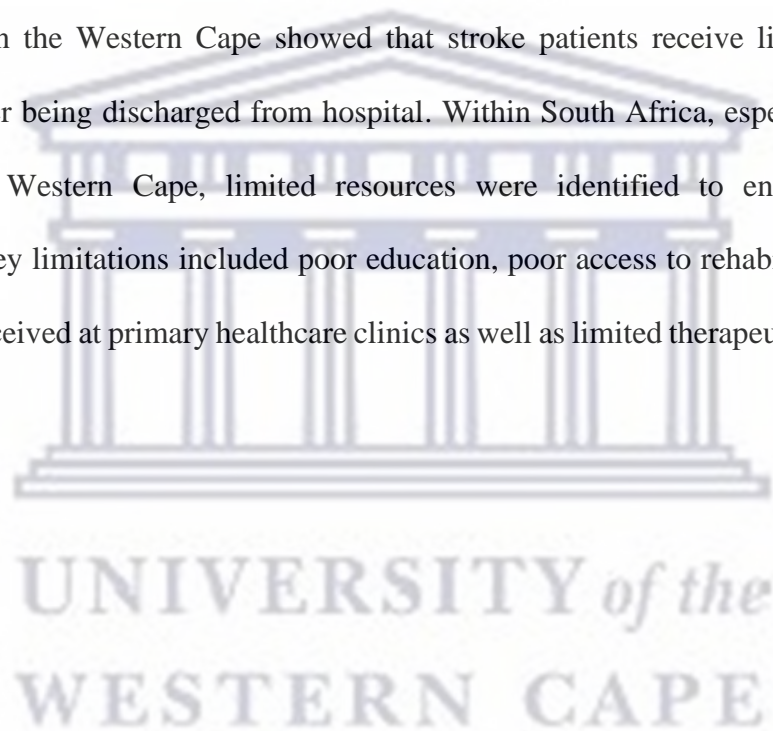
For the purpose of this study, the theory of the Occupational Adaptation Model (OAM) was used as the interaction between personal and environmental aspects, which are important for community reintegration. The factors that are important to achieve community reintegration may differ from patient to patient. The factors that may be included could be independence in basic ADLs, work-related tasks, and the adaptation to new or existing roles. The occupational therapist will assist the patient with an adaptive response to achieve mastery in the identified tasks they would like to master. The model was used to guide how each participant's personal

functional limitations and environmental factors interacted to develop either a desired adapted response to improve their community integration or community dysfunction.

2.8 Summary

In conclusion, the literature highlights the impact of stroke on the community globally as well as within South Africa. Furthermore, the literature emphasises the importance of stroke rehabilitation to ensure that stroke survivors integrate back into their communities.

Literature within the Western Cape showed that stroke patients receive limited healthcare intervention after being discharged from hospital. Within South Africa, especially within the context of the Western Cape, limited resources were identified to ensure community reintegration. Key limitations included poor education, poor access to rehabilitation services, poor services received at primary healthcare clinics as well as limited therapeutic interventions.



CHAPTER THREE

Methodology

3.1 Introduction

This chapter describes the methodology used in the current study. This chapter will focus on the aims and objectives of the study, the theoretical paradigm and the methodological research design and approach. Furthermore, the participant selection and recruitment process that was utilised within the research setting is explained as well as the data collection methods that were used in the study. The ethical considerations of the study as well as how trustworthiness was ensured are provided.

3.2 Research Paradigm and Research Design

This study was grounded within the social constructivist's paradigm. Social constructivists seek to understand the subjective experience and meaning of a specific phenomenon (Creswell & Creswell, 2018). For the purpose of the current study, participants were given the opportunity to share their experiences and feelings of community reintegration after receiving occupational therapy in their own context or world. Descriptive qualitative research designs focus on the basic nature and shape of experiences and will allow the researcher to gain an understanding on what the participants are experiencing (Sandelowski, 2000). An exploratory qualitative design focusses on the exploration of an under-researched aspect of social life (Creswell, 2007).

In the current study, an exploratory descriptive design was utilised to explore and describe stroke participants' perspectives of community reintegration after receiving occupational therapy intervention at a district hospital in the Western Cape. Each participant's transcript was explored in order to provide a common essence of the stroke participants' experiences of community reintegration.

3.3 Research Approach

Qualitative research explores the socially constructed nature of a person's reality, it is an intimate relationship between the researcher and what is being studied with the situational constraints shaping the inquiry (Denzin & Lincoln, 2011). A qualitative approach has the ability to open a descriptive human experience within a natural setting, as experienced in everyday life (Magilvy & Thomas, 2009). The process in qualitative research initially starts with philosophical assumptions or problems that the researcher has, and the researcher brings their own beliefs to the research (Creswell, 2007). This study adopted a qualitative research approach as it described the participants' own experiences from their own perspective to present objective truths. In-depth exploration and detailed understanding of the stroke survivors' own experiences or phenomenon of community reintegration within their community after receiving occupational therapy services was explored and described. Therefore, a qualitative research approach was appropriate for this study.

3.4 Study Setting

The research setting for this study was situated within the Western Cape Province in South Africa. The South African health system is largely within the public sector and is funded by the state government. According to Steve Biko Academic Hospital's website, the public sector of South Africa is divided into four sectors namely: (i) primary healthcare, (ii) district hospitals, (iii) tertiary hospitals; and (iv) central hospitals (Department of Health, Gauteng). A future health service for the Western Cape plan was developed for 2030. The plan focuses on addressing burden of disease, increasing the wellness of communities and to ensure patient-centred quality of care. The plan further builds on the comprehensive service plan by strengthening community based services, primary healthcare and district hospitals (Western

Cape Department of Health, 2013). The study was conducted at a district health facility in the Western Cape.

The hospital operates in the Tygerberg, Eastern Health District of the metro region. The Tygerberg Health District is centrally situated in the metropolitan area. According to Census 2011, 66% of the population of the catchment area is predominantly coloured, 19% black African and 10% white. About 88% of the area's population live in a formal dwelling with access to piped water inside the dwelling as well as access to electricity. Forty-five percent of households in the Eastern Health District have a monthly income of R3200 or less (City of Cape Town 2011 Census, 2013). The hospital has 273 available beds. The hospital has an Emergency Care Unit that operates 24 hours of the day. Healthcare is provided with a holistic approach and stroke patients admitted to the hospital receive rehabilitation in a multidisciplinary team setting. Currently, the multidisciplinary team consists of the following team members: medical doctor, physiotherapist, occupational therapist, speech therapist, dietician, social worker, and nurses. The occupational therapy department consists of one permanently employed occupational therapist and two locum occupational therapists working five hours per day from Mondays to Fridays. Once patients are discharged from the hospital, they are referred to community health clinics or seen as outpatients at the hospital. Patients will receive an outpatient date depending on the catchment area they live in.

3.5 Participant Recruitment and Sampling

Participant recruitment refers to the process whereby the researcher selects participants from a target population (Robinson, 2014). The researcher recruited participants by selecting only stroke participants from the occupational therapy department at the hospital who were receiving outpatient therapy at the hospital. All the stroke patients received an information leaflet explaining the purpose of the study. Once the participants gave consent to participate in

the study, they were purposively selected according to the inclusion criteria for the study. Sampling refers to a group of people or objects that will be taken from a large population to measure a specific phenomenon (Maxwell, 2009). Sampling is an integral part of the study as the population may be large and as it may be difficult to investigate each member of the population only a selected few will be able to participate in the study. The purposeful sampling was used in the study for the intention of participant selection. Purposeful sampling refers to the selection of information-rich cases related to the phenomenon (Palinkas et al., 2015). Purposeful sampling has several important uses. The researcher used the knowledge or expertise about a specific group to select participants who would best represent the population.. Qualitative research sampling size varies and depends on multiple factors, including the type of data collected, the time available, the resources, the answers the researcher is looking for as well as the theoretical framework. Patton (as cited in Butina, 2015, p.192) suggests that the researcher determines a minimum sample size and increases it only if necessary to reach redundancy. Therefore, the researcher decided on a minimum sample size of 12 (ten participants and two key informants). Ten participants were selected from the occupational therapy department who were currently receiving outpatient therapy at the hospital. The potential participants had already been reintegrated into their communities, which ultimately adhered to the inclusion criteria.

The following inclusion criteria were applied: 1) Diagnosed with a stroke not more than two years ago, 2) Adults between 18-70 years old, 3) Male and female participants, 4) Participants should have been reintegrated into the community, 5) Participants should communicate in Afrikaans, Xhosa and/or English, and 6) Participants should have received or are still receiving occupational therapy services.

Exclusion criteria were as follows: 1) Participants with aphasia, 2) Psychological diagnosis prior to stroke, 3) Participants with cognitive fallout, and 4) Participants with physical disabilities not related to the stroke.

Key informants refer to individuals who are well informed about the specific data being collected, are accessible and may even provide leads on additional information (Creswell & Creswell, 2018). The two key informants that the researcher approached were the occupational therapist and the physiotherapist who were both working at the hospital during the time of the interviews. The key informants assisted with a better understanding of the community reintegration of stroke survivors as they both continued with stroke interventions on an outpatient basis, thus continuously assessing the level of community reintegration of the stroke participants.

Participants for the study were selected by contacting the occupational therapy department at the hospital. The inclusion and exclusion criteria were communicated with the chief occupational therapist. A list of potential participants was provided to the researcher. The researcher contacted each potential participant on the list telephonically. The objective of the study was explained to all potential participants. Information sheets as well as a consent form were sent electronically to all potential participants who voluntarily agreed to participate in the study. The researcher received a total of 40 potential participants, where six were deceased, and 14 met the criteria. While four participants did not agree to participate in the study. Three key informants were identified to participate; however, one key informant did not agree to participate in the study. All participants experienced a first ever stroke. All participants received in-patient and out-patient occupational therapy at a district hospital in Western Cape. All participants were reintegrated back into the community. See table 3.1 below.

Table 3.1: Description of participants

Participant	Gender	Age
Participant 1	Female	75
Participant 2	Male	64
Participant 3	Male	75
Participant 4	Female	62
Participant 5	Male	52
Participant 6	Female	51
Participant 7	Female	45
Participant 8	Male	49
Participant 9	Male	71
Participant 10	Female	62
Key informant 1	Female	Occupational therapist
Key informant 2	Female	Physiotherapist

3.6 Data Collection

In the current study the researcher made use of semi-structured interviews for data collection. Semi-structured interviews are personal and intimate; while open, direct, verbal questions are used to elicit detailed information (Whiting, 2007). Semi-structured interviews are verbal interchanges where the researcher attempts to elicit specific information from the source through questions (Clifford et al., 2010). This method ensured flexibility for the researcher in

terms of data collection, as the researcher could modify questions during the interview process. According to Whiting (2007) certain attributes will be used to guide participant selection. These qualities include knowledge about the topic, the ability to reflect and give detailed information about the topic that is being researched and the willingness to talk. The researcher prepared the interview questions prior to the interview and allowed the participants to express their experiences freely on how they reintegrated into the community. In the current study, one individual face-to-face interview and 11 telephonic interviews were conducted with each of the ten participants (Appendix 3). Telephonic interviews were conducted with both key informants (Appendix 4). All interviews were conducted in either English or Afrikaans as per participants requests. The need for a translator was not required. The researcher asked questions relating to the objectives of the study. The interviews continued until saturation of data occurred. The interviews were conducted either at the hospital or telephonically in a venue and time convenient for each participant and key informant. Prior to all interviews, the researcher introduced herself and explained the objective of the study as well as received written or verbal consent within the participants' preferred language of choice. The researcher received consent for all interviews prior to the interviews being recorded using audiotape recordings. The timeframe of the interviews was planned to last approximately 30 minutes. During the interviews, the researcher made use of prompt techniques in order to elicit information that was not clear from each participant. Semi-structured interview questions allowed the researcher to ask new questions from the participants' responses. The researcher continued with the interviews until saturation occurred from each participant. Due to the current COVID-19 pandemic, safety protocols were ensured as per government regulations. As per hospital protocol, all visitors at the hospital underwent a screening at security prior to entering the hospital. The researcher and participant wore masks during the interview. The mask covered the mouth and nose at all times during the interview. The researcher ensured that social distance

rules were adhered to, by ensuring at least a distance of 1.5 metres between the researcher and the participant at all times. The researcher ensured that disinfectants were available at all times prior, during and after the interviews.

3.7 Data Analysis

All transcribed data was analysed thematically. Thematic analysis can be defined as a process where qualitative data is being interpreted into identified patterns or themes and describes the data in rich detail (Braun & Clarke, 2006). In the current study, the six steps as suggested by Braun and Clarke (2006) were used to analyse the transcribed data of all the interviews. The first step in the analysis was when the researcher *familiarised* herself with the data. This process involved transcribing the data from each of the 12 interviews done with the ten participants and the two key informants verbatim, reading the data several times and noting down ideas to become familiar with the data. The researcher became familiarised with the data by re-reading the transcribed data several times and got a thorough comprehension of the data. The second step involved *generating initial codes*, where the researcher collected codes of interest across the data, which provided a context of understanding the experiences of the participants. During the coding process, the researcher read through all the transcripts several times, noting down or highlighting key aspects with different colours. The researcher then grouped and numbered these highlighted key aspects into a separate document. The researcher was able to group these key aspects into different categories. The third step in the analysis involved the *searching for themes*. This is where the data that was coded in step two, was grouped into relevant themes. The researcher ensured that each theme was credible, as initial themes were reviewed multiple times. The fourth step was when the researcher *reviewed themes* by generating a thematic outline of the analysis. The researcher had to ensure that the themes correlated with the codes and the data. The fifth step involved *defining and naming themes*. This allowed the researcher

to name and refine the relevant themes while exploring the relationship between the different themes. The fifth and final step involved *producing a report*. This allowed the researcher to use the data to write up the analysis of the data. The researcher used supporting quotes from the data to complete the analysis to illustrate each theme.

3.8 Trustworthiness

Trustworthiness in research refers to when findings are as close as possible to reflect the meanings as explained by the participants (Lincoln & Guba, 1985). The researcher ensured trustworthiness of the data within the study by making use of four strategies proposed by Krefting (1991). The four strategies included credibility, transferability, dependability and confirmability.

3.8.1 Credibility

Credibility refers to the method the researcher used to interpret the findings (Crowe et al., 2015), as well as the confidence the researcher has in the truth of the findings (Krefting, 1991). Semi-structured interviews with the participants ensured credibility. Triangulation refers to the use of multiple methods or data sources within an investigation to collect and interpret the data regarding a study (Brink et al., 2018). Creditability was ensured through triangulation and member checking. To ensure triangulation within the study, the researcher used the data from both the stroke participants and the key informants during data collection. Member checking refers to when the researcher asks for the participants' opinions of the reconstruction of the information conducted by the researcher that was obtained from the interviews (Krefting, 1991). This was done by checking the data and conclusions with the participants. The researcher ensured that the interpretation of the data represented what the participants said by using a clarification process throughout the interview.

3.8.2 Transferability

Transferability should be able to provide detailed findings that can be applied to other similar contexts (Curtin & Fossey, 2007). Transferability was applied by providing detailed and rich information in order for the findings to be transferred to a specific situation through thick descriptions by paying close attention to detail by observing and interpreting the meaning of findings.

3.8.3 Dependability

Dependability involves a process of providing adequate information on the data collection and data analysis to allow the decision-making trail to be followed (Crowe et al., 2015). Dependability was achieved through dense descriptions by paying close attention to detail and interpreting the participants experiences. The researcher ensured that all findings within the current study were not that of the researcher but rather that of the stroke survivors' perspectives of community reintegration.

3.8.4 Confirmability

Confirmability refers to the degree to which the results could be confirmed or supported by others (Krefting, 1991). Confirmability was ensured with a confirmability audit by formulating themes from the data collected. An audit trail was achieved by providing raw data, and analysis of notes to the study supervisors.

3.9 Ethics

Ethics clearance was obtained (Appendix 6) from the University of the Western Cape (UWC) Bio-Medical Research Ethics Committee (BMREC) (Ethics Clearance Number: BM20/8/15). After ethical clearance, the study was registered on the National Health Research Database (NHRD). Permission from the hospital was obtained by the Provincial Health Research

Committee (Appendix 7) to conduct the study by explaining the research aims and objectives thereof. Once permission was granted, the researcher approached the participants and provided the participants with information regarding the study and invited them to participate in the study through verbal explanation. The researcher provided all potential participants with the Information letter (Appendix 1) in order for the participants to understand what the researcher was attempting to achieve through this study. The researcher then obtained participants' written or verbal informed consent (Appendix 2).

The ethics principle of autonomy was applied by making use of a verbal explanation to all participants that they were consenting voluntarily to participate in the study and that they had the right to withdraw from the study at any time without being penalised. The researcher upheld the principle of veracity by being truthful and honest at all times. The researcher also ensured that all participants were well informed about the specific nature of the study. The participants were assured that all information recorded or collected was verified by only the researcher and that all information was stored in a safe place on a computer that only the researcher had access to. To address the principle of privacy, all data collected was stored in a locked cupboard that only the researcher had access to. All data saved on the computer was kept private with a password only the researcher was able to access. The researcher will have access to the data for a period of five years after which all data will be destroyed. The researcher made use of pseudonyms to ensure confidentiality when reporting the findings of the study. Therefore, anonymity was ensured. Beneficence was ensured by providing the occupational therapy department at the hospital with recommendations for future implementation. Non-maleficence was endorsed by providing the participants to an appropriate organisation or person in case debriefing was required. Participants were provided with the option of a counsellor post interview; however, all participants declined the offer. All interviews were structured in terms of venue, dates, and times to accommodate the participants' choice and schedules.

3.10 Summary

Within this chapter, the research paradigms of social constructivists, the explorative descriptive design and the qualitative research approach were described. The methods of data collection namely, semi-structured interviews as well as the data analysis process were also described. Furthermore, in this chapter, the research setting as well as the selection and recruitment process used were explained. Lastly, the strategies to ensure trustworthiness and ethical standards were explained. In the next chapter the findings of the study will be presented.

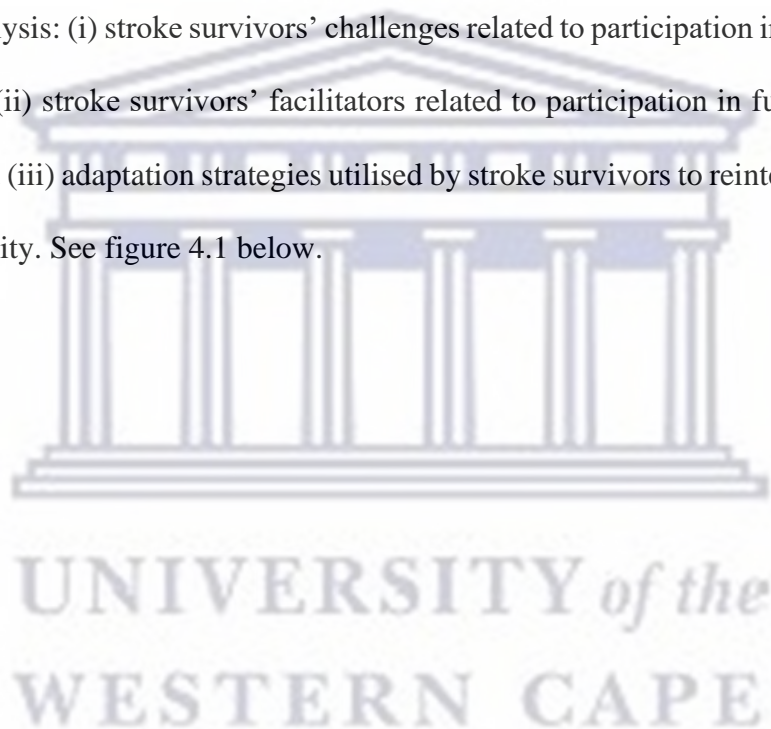


CHAPTER FOUR

Findings

4.1 Introduction

This study aimed to explore and describe the perspectives and experiences of stroke survivors' community reintegration after receiving inpatient occupational therapy intervention at a district hospital in the Western Cape. This chapter presents the findings of themes, subthemes and categories that emerged from the thematic analysis. The following three themes emerged from the thematic analysis: (i) stroke survivors' challenges related to participation in functional tasks or occupations, (ii) stroke survivors' facilitators related to participation in functional tasks or occupations, and (iii) adaptation strategies utilised by stroke survivors to reintegrate back home and the community. See figure 4.1 below.



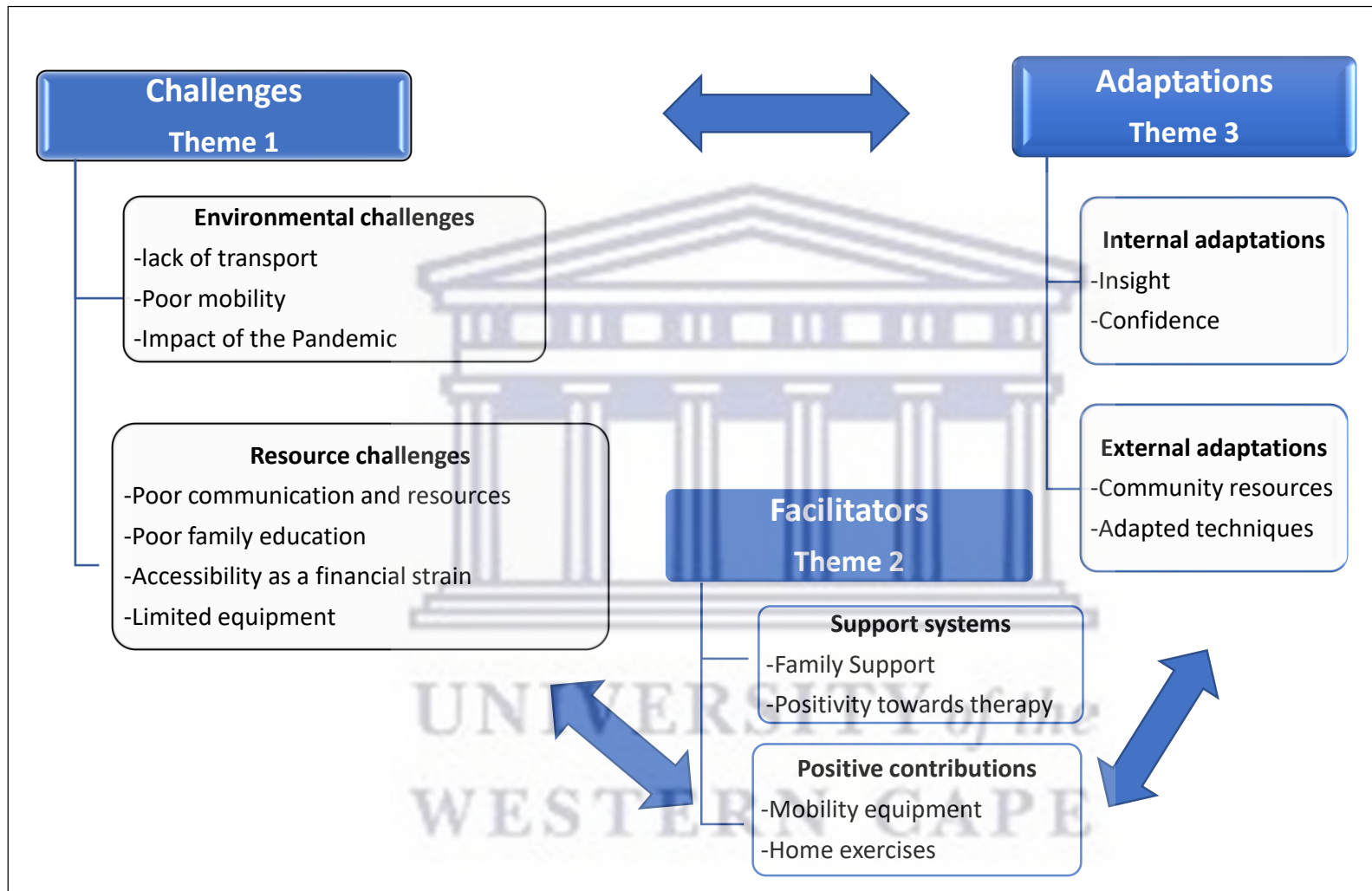


Figure 4.1: Themes 1-3: Stroke survivors' challenges, facilitators and adaptations

4.2 Theme 1: Stroke Survivors' Challenges Related to Participation in Functional Tasks or Occupations

Theme 1 represents the participants' experiences with challenges within their environment and limitations of resources available to the stroke survivor. Limited access to transport, mobility within the community as well as the impact of the Covid 19 pandemic forms part of the environmental challenges experienced. The stroke survivors also experienced poor holistic interventions due to limited MDT and family communications, the ability to reach therapeutic services due to financial constraints and the limited availability of equipment. See table 4.1 below.

Table 4.1: Theme 1 stroke survivors' challenges, subthemes and categories

THEMES	SUBTHEMES	CATEGORIES
Stroke survivors' challenges related to participation in functional tasks or occupations	Environmental challenges experienced by the stroke survivor	<ul style="list-style-type: none"> • Lack of access to transport to travel within the community • Mobilising within the community is a struggle due to my hemiplegia • The Covid-19 pandemic impacted

	<p>Resource-related challenges experienced by the stroke survivor</p>	<p>therapeutic continuity</p> <ul style="list-style-type: none"> ➤ Poor communication within the MDT and limited therapeutic resources impacts therapeutic services. ➤ Poor family education negatively affects reintegration at home ➤ To access therapeutic services is a financial strain ➤ Limited availability of equipment impacted functional independence
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4.2.1 Environmental challenges experienced by the stroke survivor

4.2.1.1 Lack of access to transport to travel within the community

In this category participants expressed their experiences on the accessibility of transportation.

Participants stated that they experienced difficulties utilising various transport systems to reach

healthcare services. The limitations within transport were confirmed by both key informants as the therapists are aware of the difficulty patients experience to reach the services. This can thus impact rehabilitation progress and continuity of the therapeutic services. One participant expressed the feelings of anxiety when travelling with public transport as he did not feel safe using the services of taxis. The participant shared that he experienced the drivers as incompetent to collaborate with people with disabilities. According to the participant this is not something he experienced once but has witnessed on various occasions.

“I have not yet made use of a taxi. I do not feel safe in the taxi, to be honest with you. A lot of them are very impatient if you are too slow to get in and out and then they will just start driving. I have seen it with my own eyes before, I am not taking any chances with a taxi right now.” (Participant 2)

One of the key aspects of utilising transport is the ability to get in and out of a vehicle. Two participants experienced difficulty when embarking or disembarking the taxi.

“One time I tried to get out of the vehicle at work, my leg gets stiff at times, and when I turned around, I fell onto my shoulder.” (Participant 3)

“On Tuesday I tried to use the taxi, but it was a problem, I couldn’t get in and out of the taxi.” (Participant 4)

Financial implications were considered another barrier for the participants in this study. Two participants articulated that financially they were unable to afford transport to access therapeutic services. One of the participants conveyed feelings of hopelessness when he stated that if the prognosis of his arm is poor, he would rather not attend therapy due to the substantial financial burden.

“If I can only see the doctor one more time, I would ask them if there is any hope left for my arm, otherwise they should not ask me to come in to the hospital anymore, because it is a lot of money for me to get there.” (Participant 3)

“They asked me before if there is any problems and I did tell them yes, the finances are the biggest problem, the biggest problem is to get to therapy.” (Participant 4)

The above statement that access to health services is a financial burden was confirmed by one of the key informants.

“But some patients don't like going to the clinics, so they want to come to the hospital but then there is transport issues or financial issues or they are living in extreme poverty areas. Access is just very poor.” (Key informant 1)

Two participants in the study stated that they have previously had access to their own private transport. One participant expressed that even though there is access to a car within the household, that their ability and confidence to drive is limited. The participants both lacked confidence to be able to drive their own car in the future. One participant articulated that not being able to drive was one of the biggest limitations he had experienced since the stroke. This obstacle not only limits access to healthcare therapy, but also the ability to resume community functions like shopping, leisure tasks and religious gatherings.

“I did drive before my stroke, but currently I don't drive at all. I don't have a car anymore, but also, I don't think I would manage anyway.” (Participant 6)

“Well, I know I can't drive anymore. That was the biggest limitation for me.”
(Participant 7)

One key informant confirmed the above statements. The key informant stated that most stroke patients do not have access to private transport, and that access in terms of the physical ability to get in and out of a car is limited, and all the above factors influence the continuation of therapy as they are unable to attend therapy sessions.

“...they don't have access to a car, how do they actually get into a car, to follow up has been difficult, very limited.” (Key informant 2)

4.2.1.2 Mobilising within the community is a struggle due to my hemiplegia

Under this category, participants reported that they experienced limitations in mobilising. Most of the participants expressed that they had made use of a mobility device to help them mobilise since they had suffered the stroke.

Two participants expressed that they received a crutch to improve their ability to mobilise. However, one participant stated that the crutch did not improve his mobility whereas the other participant stated that he used the crutch when mobilising over uneven surfaces. One participant voiced fear of falling, resulting in a lack of confidence to mobilise outside of their home environment thus limiting community participation.

“I use the crutch when the floor is uneven, I am too scared that I might fall, otherwise I walk without it now.” (Participant 2)

“The only thing I received was one crutch and it didn't really help a lot with walking. They always have to help me, or my wife helps me.” (Participant 3)

As functional mobility is one of the key aspects to resume daily tasks the inability to mobilise within their own household or community can have a significant impact on the return to pre-morbid function. One participant communicated that therapeutic interventions needed to focus more on walking abilities.

“The walking was very difficult for me to do. They need to focus their therapy to help people walk again.” (Participant 4)

The ability to mobilise has various components. One of these components is the ability to navigate stairs. One participant said that stair climbing is still of a concern and that elevators are preferred. Therefore, if there is no access to elevators this participant may experience difficulty in navigating stairs.

“I will not easily use the stairs; I prefer to use the lift.” (Participant 8)

While most participants stated the inability to mobilise outside over uneven surfaces or use various other methods to navigate stairs, this participant stated that he is mostly bedbound. The participant stated that he does make use of a rollator, but nothing is mentioned about mobilising within the community. The participant’s mobility is confined to their home environment only, thus limiting community participation.

“I am mostly bedbound, I will try to walk with the rollator to the TV-room from the bedroom, I do manage, I do manage.” (Participant 10)

4.2.1.3 The Covid 19 pandemic impacted therapeutic continuity

All participants as well as both key informants perceived the Covid-19 pandemic as a limitation towards therapeutic interventions. During the pandemic, various protocols were put in place to curb the transmission of Covid-19. One of these protocols involved limiting contact with people, resulting in isolation. The continuation of therapy was limited by these protocols.

Post discharge stroke patients receive home based care (HBC) referrals. Nursing staff visit stroke patients within their home environment. They assist families in need and do referrals if any problems arise once the participants are back home. Due to the pandemic, the HBC services were limited and as stated by one participant, the nurses were not allowed to touch the participants.

“...home base care...they did come and visit us, but they did not do anything, because they cannot touch. That is now the community nurses that is making their rounds up and down.” (Participant 1)

Therapeutic intervention is a holistic approach where family members need to be involved in therapy for various reasons. Participants articulated that due to the pandemic, family members were not allowed to accompany patients to therapy sessions. This could have resulted in the loss of educational information as some stroke patients may have had cognitive impairments.

“Yup, they did give training, until the day that they told us she can't come with me anymore as they do not want too many people in the hospital anymore because of covid.” (Participant 2)

Another participant felt that his family was unprepared on the day of discharge. The participant voiced that his wife did not receive any information regarding his condition prior to discharge.

"I do understand that it is Covid, but there is at least a thing like a telephone, they could have at least phoned her, and share some of the information with her, so that she could prepare herself for when I had to return home." (Participant 5)

Another restriction one of the participants experienced was the inability to return to work. Due to the pandemic, not all labour departments were seen as essential services and had to close their doors during the pandemic. This influenced one participant's ability to return to work.

"The one big positive for me was that the OT thought that I was able to actually try and get back into the workforce. She gave me all the details and information to get hold of a place that actually place people with disabilities... but unfortunately Corona hit and that was not happening anymore." (Participant 7)

It was confirmed by both key informants that family training during the pandemic was constricted. Prior to the pandemic family training was part of therapeutic intervention before discharge in order to prepare family members and to prevent any secondary complications.

"Before covid we used to do a lot more family trainings we could have done at least two or three throughout admission or whenever the family was visiting now due to covid we can't, do as many family trainings as we want, we can only do one." (Key informant 1)

"We still do training umm but I must say if I think about it now not as much, because in the past they would be able to have more than one family member coming, now it is limited to one member coming in." (Key informant 2)

4.2.2 Resource-related challenges experienced by the stroke survivor

4.2.2.1 *Poor communication within the MDT and limited therapeutic resources impact therapeutic services*

Communication within the MDT refers to the doctor, nursing staff, therapists, social workers and family members being involved during crucial decision making during the rehabilitation process. Participants in the current study felt that there was a lack in communication within the team while the key informants stated that they experienced a lack of resources in terms of limited staff when treating patients.

One participant in the study shared that he did not experience a holistic team approach. The participant stated that the treating therapist still planned specific therapeutic interventions; however, the participant was discharged prior to this. The participant expressed that he felt that the team members did not communicate with one another. This was confirmed by one of the key informants. The key informant recorded that they experienced delayed referrals due to poor communication within the MDT, thus, influencing a safe discharge home.

“I feel that the communication between the doctors and therapists requires attention. The doctor discharged me on Saturday without liaising with the others. It is like the right hand does not know what the left hand is doing. This might also be the reason why there was no communication with my family members.” (Participant 5)

“Sometimes due to a high patient load the OTs don’t always get referrals early or they will only be referred to one rehab team member and we as OTs will only get referred much later and then we only speak to the family later or discharge is coming up too soon and we haven’t spent enough time with the patient. That directly affects how they return to home slash work if they work. Sometimes miscommunication, the late referrals and then the early discharge of patient or discharge without OT being involved

sometimes leads to the fact that OTs can't spend so much time with them, and the patient is about to be discharged the next day. So, you couldn't spend much time with the patient or spend enough time talking to the family, so yes on that side the lack of holistic approach from that point does make a difference in how the patient reintegrate back into their day to day.” (Key informant 1)

Another participant conveyed that follow-up therapy was delayed and that he had a long wait for a follow-up date. Lengthy waiting lists have been an ongoing barrier within the public healthcare sector in South Africa. A delayed therapeutic input can directly impact the functional outcome of stroke survivors. One key informant expressed that the OT department experienced a lack of staff members for the workload they received. The OT department currently only has one permanent OT, and two locums who work half day shifts. The key informant argued that the high patient load of inpatients and outpatients could be one of the contributing factors as to why patients have to be on long waiting lists prior to receiving outpatient therapy.

“One thing I can say is that I would have liked to get therapy quicker, you know to get an earlier follow-up date.” (Participant 6)

”Limited time is spent with patients due to it being an acute setting and due to it being a high patient load, and still having to deal with outpatients. So I think knowing that you have one staff member two locums but the workload or the patient load that is given is for at least four OTs working there. So, what happens is that the OTs working within the OT department cannot give as much time as they would like to each patient because they have to get through all the patients every single day”. (Key informant 1)

Again, limitations in staff-related issues featured, and the key informant was aware that additional services could potentially benefit the patient. However, due to a shortage of staff, home visits were not viable. The key informant also stated that not all clinics in the community have therapeutic services, so the patients from these specific catchment areas are referred back to the district hospital for therapy, adding pressure to the already increased workload of the staff.

"We don't have the capacity to do home visits, I think they have done it in the past, but I think the patient load is just too much. Some clinics do home visits that I am aware of, but not all clinics have therapists. So, for example in our area I think Parow Clinic for example it's a clinic, but there's no therapists. They refer to us, so we see those patients as an outpatient patient. This is in an acute hospital where you see the acute conditions, so the long-term care where we can we refer to umm the community resources." (Key informant 2)

4.2.2.2 Poor family education negatively affects reintegration at home

Family and caregiver education and training is a vital part of stroke rehabilitation. Education and training encourage a smooth transition from the hospital into the community.

Participants communicated that family members received minimal training prior to being discharged back home. Three participants mentioned that family members received no training prior to them being discharged. One participant stated that education is important as this is a new adaptation for both the participant and the family. One participant suggested that family meetings could be integrated as he felt that his family members expected too much and did not understand the gravity of his condition.

“I would not say that she received any training, it was only the staff nurse that spoke to my wife when I was discharged. She only spoke to her in general she did not receive any form of training. So if you know these things beforehand, almost like to be more educated in terms of the stroke. And also to educate the family, it is also the first time they are experiencing something like this, and how to handle these patients.”
(Participant 5)

“On my side, my family didn’t really help much when it came to my recovery. Well, my sister is fine, but my brother in law that side of the family they don’t understand, they think that I should just be able to do anything anyway... So before they reintegrate the patient to the family, I think family meetings would help a lot, yes I think that would help tremendously.” (Participant 7)

“No, my wife did not receive any training from the therapists.” (Participant 10)

Another key informant mentioned that due to a lack of education, family members of the patients may find it difficult to comprehend the training sessions they receive, resulting in poor compliance. One key informant did however mention that the focus should be more directed towards the carer with multiple education and training opportunities.

“There is a decrease or lack of education, so a lot of our patients are not... they don't always have matric they had to leave school for work and it comes down to that if you explain certain things in the most layman terms you can use, like explaining what's happening to the body or explaining why therapy is important many don't understand or fully comprehend what has been told or advised. So, they don't always want to return for follow-up dates if we look at post hospital receiving treatment from OT.” (Key informant 1)

“I think the main focus should be on the carer. I think it should be on the carer, educating the carer and training, follow ups and if the carer could afford it to have more than one session with the carer. We haven't even had a lot of family trainings, umm but we do, do it, it is just limited to one family member, and it is not as much. It is literally one session in a short period of time, we give them a home programme.” (Key informant 2).

4.2.2.3 To access therapeutic services is a financial strain

The majority of participants articulated their concern about the financial strain they experienced in order to reach therapeutic services. Public transport in South Africa is limited with poor accessibility for disabled persons. Most busses and taxis in South Africa are overcrowded making it difficult to transport various adaptive equipment in them.

One participant stated that he lost his income and can no longer afford the transport costs to the hospital. Another participant mentioned that they have to borrow money to afford the multiple taxis they needed to take to get to the hospital.

“I would ask them if there is any hope left for my arm, otherwise they should not ask me to come in to the hospital anymore, because it is a lot of money for me to get there. Every time I have to spend R300.00 to give to the man that brings me in, and he has to wait there the whole day. This month I can still afford it because I will receive something from work, but that money will be used to take me to the hospital again.”

(Participant 3)

“They asked me before if there is any problems and I did tell them yes, the finances is the biggest problem, the biggest problem is to get to therapy. It is a problem, we have

to borrow money every time to get there, because we don't have our own transport."

(Participant 4)

One key informant confirmed the above struggle stroke patients had experienced and that they were aware of the financial implication affecting attendance in therapy. The key informant stated that they do, however, make referrals to closer clinics, but patients would rather return to the hospital if possible, and some clinics do not offer therapeutic services, resulting in the financial strain stroke patients find themselves in when accessing therapy.

"But some patients don't like going to the clinics so they want to come to the hospital but then there is transport issues or financial issues or they are living in extreme poverty areas. Access is just very poor." (Key informant 1)

4.2.2.4 Limited availability of equipment impacted functional independence

A few participants indicated that they received little equipment to improve their functional abilities. One participant said that he found it difficult to mobilise within the community because he did not receive any devices to improve functional mobility from the therapist, thus resulting in the inability to attend religious gatherings in the community.

"No, I didn't receive anything from the hospital. It is difficult to go to church now as I am not able to walk anymore." (Participant 1)

Two participants mentioned that they experienced difficulty with food preparation and the ability to dress. Occupational therapists are able to issue various food preparation and self-care assistive devices. These assistive devices enable a person to perform various food preparation

and self-care tasks. However, due to lack of availability of the devices, participants were unable to perform their tasks independently.

“Because I am unable to hold the potato or onion in my hand and cut with the other hand. I am also unable to hold a bowl when trying to mix ingredients. So, making food was very difficult for me. It was difficult to adapt at home, I was for instance able to dress myself, but I couldn’t fasten my own buttons.” (Participant 4)

“When I am holding a potato in my left hand and I want to peel it with my right hand, then my right hand suddenly becomes numb, and it slips out of my hand. At this I change clothing as little as needed. I am in my pajamas most of the time.” (Participant 6)

One participant expressed that he was able to buy various assistive devices privately. He did however also receive the advice from his treating OT as well as from people within his immediate environment at home.

“Initially I had to buy myself specialised sponges to wash my back, or to put cream onto my back. You know the therapists at the hospital didn’t give me these things. I have occupational therapy colleagues that work with me that advised me on these things. In fact the one lady actually bought a few of these items for me as a present. I didn’t receive any equipment from the hospital, but they did advise me on what to buy and what items are easily accessible. I would really like the therapists at the hospital to have given me more information on the options available to improve my independence and quality of life.” (Participant 8)

One key informant shared her views regarding equipment. The key informant said that due to limited budget allocations the OT department was unable to issue assistive devices as indicated

in her statement below. The key informant suggested that it could benefit the patients functionally if they were able to issue various pieces of equipment directly to patients.

“So, in other facilities people can sometimes get shower benches, or special knives, spoons with grips and so on. But here due to the resources and how much money each hospital gets given a lot of our funds go towards wheelchairs and splinting material. We sometimes try to make certain things like build up grips ourselves. We are well aware of the assistive devices available especially when it comes to cutting boards, knives, dressing equipment and all those things that we know about but don’t actually purely have the resources for it. But we do give suggestions to purchase elsewhere so a lot of the patients are aware of Dischem and other pharmacies where they would be able to buy these items.” (Key informant 1)

4.3 Theme 2: Stroke Survivors’ Facilitators Related to Participation in Functional Tasks or Occupations

This theme represents the participants’ experiences in systems that supported rehabilitation and positive aspects that enhanced function. A supportive family structure and the satisfaction towards therapy and the therapist were seen as enablers in the rehabilitation process, while specifically, mobility devices that enhanced mobilisation and the issue of home exercise programmes contributed to improved functional outcomes. See table 4.2 below.

Table 4.2: Theme 2 stroke survivors' facilitators, subthemes and categories

THEMES	SUBTHEMES	CATEGORIES
Stroke survivors' facilitators related to participation in functional tasks or occupations.	<p>Supportive systems that enable the stroke survivor to complete rehabilitation</p> <p>Positive contributions that facilitated improved function</p>	<ul style="list-style-type: none"> • A supportive family enables participation in occupations • Stroke survivors had a positive attitude towards therapy and the therapists that treated them <ul style="list-style-type: none"> ➤ The availability of mobility equipment assisted with improved mobilisation ➤ The issue of a home exercise programme was seen as a valuable contribution to improve function

4.3.1 Supportive systems that enable the stroke survivor to complete rehabilitation

4.3.1.1 A supportive family enables participation in occupations

All the participants expressed that they valued the support and involvement they received from family members and close friends. One participant stated that the family was aware of the functional shortcomings and that the family assisted where he was unable to. One key informant also emphasised the importance social support plays in the rehabilitation of stroke patients.

“No at the moment everyone is very supportive, they encourage me to keep exercising the hand it will improve just like the leg.” (Participant 2)

“You know, they understand. They really understand that there is certain things I cannot do anymore and they help me.” (Participant 4)

“Yes, I don’t have anyone else that can help me, only my wife. She does everything for me and that is why I appreciate her so much. Almost every night since the stroke my friend is at our house and asks how I am doing.” (Participant 3)

“A lot of them were very shocked to see me in this state. But I have to say that the support I received from everyone was very positive.” (Participant 5)

Not only did one participant mentioned his family being supportive but also a work colleague who understood what he was going through. This meant that the participant could resume his work duties and earn an income and not feel isolated in the workspace.

“Like when we are at work and I call him while I am using the toilet and I struggle with my pants’ buttons then he will help me to with that and I appreciate that a lot from him.” (Participant 3)

This was verified by one of the key informants who stated the importance of social support from family members to integrate back into the community.

“If I look at the patients who have experienced it most of the time it is actually just social support.” (Key informant 1)

4.3.1.2 Stroke survivors had a positive attitude towards therapy and the therapists that treated them

Most participants pointed out that they were satisfied with the services they received from the therapists. The participants provided positive responses related to their treatment and service providers. Participants also conveyed feelings of gratitude towards the therapists.

“What I would like to add is that both the OT and the Physio know what they do. How can I state this, they are not ‘chancers’ and is well equipped to do their jobs. I am very proud to be here. My arm was so stiff and the lady who helped me did a fantastic job. I can’t comment on anything that they have to change because so far I have been 100% satisfied with the service. The way they do things I am very satisfied with.” (Participant 2)

“No there is not really anything. Because the therapists just try to do their best they can to help me and to show me what to do to improve. No I am very satisfied with them.” (Participant 3)

One participant commented that the therapeutic plan from the therapist benefitted him, even though he did not realise the importance of therapy in the initial stages. With positive reinforcement from the therapist, the functional outcome of the participant also improved.

“They were most definitely beneficial. The exercises they gave me definitely helped. As the time went on, I started seeing the benefits in the exercises they gave me, I didn’t see it immediately, but through the process I did. They also encouraged me to put more effort in from my side too.” (Participant 5)

Another participant felt emotional about the therapy he received and stated that God used the therapist within his life after the stroke.

“Yes, it was very good. The therapy I received were very good. I thanked them and even cried because God used them to work with me, and it was very good.” (Participant 4)

4.3.2 Positive contributions that facilitated improved function

4.3.2.1 The availability of mobility equipment assisted with improved mobilisation

A few participants expressed that they had positive experiences regarding the use of the mobility devices they received and being able to walk. One participant stated that he received a crutch and that he used it to attend church, thus being able to resume community participation and attend religious gatherings again.

“Look before the stroke I was able to walk without a crutch, but now I am making use of the crutch to go to church. Let me explain it like this, when I arrived at the hospital on the 4th of December, I was completely unable to walk. It was the OT that showed me what to do and how to get to the toilet. I then continued with that at home and then I was able to do it.” (Participant 2)

Another participant stated that not only did he receive a crutch but also an ankle foot orthosis (AFO). The combination of the crutch and AFO resulted in improved mobilisation.

“The only thing I received was one crutch. And I have to say that it really helps me a lot with walking. I also received a specific shoe it is this strange plastic thing that help me to walk better.” (Participant 3)

Two other participants made use of walking frames and stated that without it they would not be able to cope with mobilising. However, it is concerning that one participant had to borrow a walking frame for improved mobilisation.

“Yes, I did receive a walking ring, I still make use of the walking ring to help me walk. Without it I would not be able to manage.” (Participant 9)

“You know, I do still struggle to walk but I can walk fairly well with the walking ring. I didn’t receive anything from the hospital, but I managed to borrow a walking ring that helps me to walk.” (Participant 10)

4.3.2.2 The issue of a home exercise programme was seen as a valuable contribution to improve function

Some participants stated that the therapist provided them with home exercises. All of the participants expressed that these home exercises helped them to regain function.

One participant stated that adapting at home was a struggle; however, the exercises he received to continue at home made the transition smoother.

“Yes, the exercises they gave me helped a lot. Yes they gave me exercises on a page that I have to do daily.” (Participant 3)

Not only were the exercises performed in therapy, but continuation of therapy was made possible in a home setting with a home exercise programme. This may have been because of

the limitation of therapeutic resources within the department as patients had to wait a long time for follow-up appointments.

“Look here they gave me a lot of exercises that I have to do at home. That helped me a lot. The type of exercises they gave me in the hospital and send home with me, definitely improved my arm.” (Participant 6)

“Well to be honest it was difficult settling back in on doing the daily things but the exercises the OT gave me helped me tremendously, without those exercises I don’t think it would have been... I mean the transition would not have been so easy.” (Participant 7)

One participant experienced doubt during the initial phase of rehabilitation. However, as he continued with therapy, he started seeing the results from the specific exercises the therapist gave him. He also stated that the OT who treated him had a good attitude in therapy and he complimented the way she treated him.

“Look here, the exercises they gave me was important to me. Initially you don’t believe that all of these things will work. Look here, I am a medical doctor, so to convince me it needs to be evidence based, do you understand? But as time went on I started seeing results and my fingers started moving. And that is where I realised that Occupational Therapy is geared to do this and this made me feel very good too. Not only the exercises but also the attitude of the OT who treated me was outstanding.” (Participant 8)

4.4 Theme 3: Adaptation Strategies Utilised by Stroke Survivors to Reintegrate Back Home and into the Community

In theme 3, all the participants communicate their adaptations and adjustments as an internal and external process to reintegrate into the community. The enhancement of insight and

confidence is driven as an internal process to adapt. While valuable services in the community, newly learned adapted techniques and equipment added value to the external process to adapt to their home environment and ultimately reintegrate into the community. See table 4.3 following.

Table 4.3: Theme 3 Adaptation strategies utilised, subthemes and categories

THEMES	SUBTHEMES	CATEGORIES
Adaptation strategies utilised by stroke survivors to reintegrate back home and into the community	<p>Adaptation strategy as an internal process to reintegrate into the community</p> <p>External aspects to reintegrate into the community</p>	<ul style="list-style-type: none"> • Gaining insight in own condition resulted in an improved functional outcome. • Confidence assisted the stroke survivor to be more capable to perform tasks that is important to the individual. <p>➤ The value of community resources for improved community reintegration.</p>

		<p>➤ The use of various new adapted techniques learnt in therapy improved functional outcomes in self-care.</p>
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4.4.1 Adaptation strategy as an internal process to reintegrate into the community

4.4.1.1 Gaining insight in own condition resulted in improved functional outcome

Most participants articulated that once they noticed the improvement, they realised that the exercises they were given did assist in improving their function. One participant noted that the OT helped them understand the effects of the stroke on their body and function, thus improving the stroke participants' insight. Insight is an important part of rehabilitation as it facilitates a positive outcome in therapeutic participation.

“The OT gave me a better understanding as to what my body was doing and she explained to me that this is why I am not feeling these things, due to the stroke, and what things I can do to create those sensations. All of those exercises she gave me was spot on, because they definitely helped me one hundred percent.” (Participant 7)

Two participants in the study expressed that during the initial phases of rehabilitation they experienced doubt in themselves. During the process, the OT aided them towards a better understanding of the rehabilitation process and through this process they gained more insight thus resulting in improved function. Once the participant started to notice that the rehabilitation process aided function, they became more positive during therapeutic interventions.

”As the time went on I started seeing the benefits in the exercises they gave me, I didn’t see it immediately, but through the process I did.” (Participant 5)

“Initially after I had my first session, I didn’t have a lot of hope because the prognosis of my hand was not looking good. But with continuation of therapy I started seeing improvement. Look here, I am a medical doctor, so to convince me it needs to be evidence based. Initially you don’t believe that all of these things will work.”

(Participant 8)

4.4.1.2 Confidence assisted the stroke survivor to be more capable to perform tasks important to the individual

Some participants communicated that they experienced an improved confidence in their own abilities. Participants conveyed negative emotions towards functional improvement after a stroke. However, through the positive reinforcement of the OT the participants own confidence improved. One participant stated that the OT encouraged independence and confidence in oneself, as one tends to lose confidence quickly after a stroke. Another participant stressed the importance of these positive reinforcements on her rehabilitation to return to the community. The participant stated that initially she would not be able to perform tasks like working on a computer anymore, but with affirmation from the OT, she started working on her computer again and was surprised of what she was capable of achieving.

“Well advice from the OT I received was to do things on my own. Just knowing that you are able to do this, to never doubt yourself was amazing advice I received. I was very hard on myself. I am working on a computer again, you know in the beginning I thought that oh no I will never be able to do this again, but surprisingly I was. We just

need that boost, that I can actually achieve this, that means the world of good actually, it is difficult we lose confidence in ourselves so quickly after a stroke.” (Participant 7)

The improved confidence directly impacted functional outcomes. One participant stated that initially his wife was doing most of his ADL tasks for him but through the process of rehabilitation, the patient’s confidence in his own abilities improved. One day he realised that he could attempt these tasks himself as he practised during therapy. As he gained more confidence his ability to do more tasks independently improved. He was able to mobilise into a church to attend religious gatherings without the use of a wheelchair.

“And then I told her but wait, I can do this myself now, and I just got up and walked to the toilet myself. And right there I did it myself, I washed my hands... I did everything myself. Even going to church, I told myself that I can walk into the church and not use the wheelchair and I showed myself that I could do it.” (Participant 2)

Another participant stated that being patient with oneself was important during rehabilitation and in order to gain confidence to perform previous tasks. Even though it might be that the tasks had to be adapted, the participant was able to perform these tasks through patience. The participant stated that he was now able to attend church and is able to go out into the community again.

“I wouldn’t say that I had to adapt too much but I had to learn to be more patient with myself compared to the way I did things previously. Like going to church or going out, I started doing all of those things again.” (Participant 5)

4.4.2 External aspects to reintegrate into the community

4.4.2.1 *The value of community resources for improved community reintegration*

All the participants acknowledged the value in community resource services they received. The value of community resources can at times be underrated. One participant and both key informants highlighted the importance of these facilities within the community to aid community reintegration. Both key informants stated the importance of community resources in order to assist the families. The hospital mainly makes use of two intermediate care facilities prior to the patient being discharged into the community. These facilities facilitated improved functional outcomes and community reintegration. Unfortunately, due to limited availability of these facilities not all stroke patients were able to be admitted to these facilities. The one key informant emphasised that it is not only the participant that benefitted from these facilities but the family members as well.

“So, the facilities we use, we are only using two at the moment and that will be M7M8 or WCRC. With these two facilities the waiting period can be so long that it, the waiting period itself can be three to six weeks. That is generally for WCRC, for M7M8 you can wait one to two weeks, however the capacity at the moment is very full so they have actually stopped accepting patients.” (Key informant 1)

“The last couple of months we actually referred quite a few patients for rehab and step down because of the time family members needed to adjust to the new situation.” (Key informant 2)

One participant stated that the OT referred her to two community resources to help improve community reintegration in driving abilities as well as work. Unfortunately, due to Covid-19, the work centre she was referred to, closed down and she was unable to attend this work

rehabilitation programme. The participant was able to attend a driving assessment after she had suffered a stroke. The driving assessment is a simulator to help establish the ability to drive. The participant made use of this community resource and was cleared for driving her own car again. However it is important to note that the driving assessment is not available in the public sector.

The one big positive for me was that the OT thought that I was able to actually try and get back into the workforce. She gave me all the details and information to get hold of a place that actually place people with disabilities... but unfortunately Corona hit and that was not happening anymore. The OT also suggested that I go and see UZEBENZA for a driving assessment. So ja, I went there and they do all sorts of tests and they said okay yes, they agree that I could go back and try and do the driving.” (Participant 7)

4.4.2.2 The use of various new adapted techniques learnt in therapy, improved functional outcomes in self-care

All the participants stated that the OT educated and demonstrated new methods of performing ADL tasks. One participant articulated that his family members had to perform all the BADL tasks for him, but through OT intervention adapted techniques assisted independence. These new adapted techniques learnt in therapy, resulted in independence in dressing and personal hygiene tasks.

“Previously my wife and son did all of it for me. But now I am able to take off the cap of the toothpaste myself and use a new way to apply the toothpaste onto my toothbrush, and now I brush my teeth myself.” (Participant 2)

Another participant voiced that simple tasks like getting out of bed independently was a struggle but with the adapted techniques he was able to perform these tasks on his own.

“But with the techniques that they taught me and the fact that I had to learn to adapt things and to use new techniques helped me to do different things.” (Participant 5)

One participant stated that his wife did not need to assist him any longer as the new techniques helped him to perform these tasks independently.

“So, the exercises she used was focussed on improving my function. Now I can do a lot more for myself. I am not reliant on others anymore.” (Participant 8)

4.5 Summary

By analysing all the participants' feedback, the aim of the study to explore and describe the perspectives and experiences of stroke survivors about community reintegration after receiving inpatient occupational therapy intervention at a district hospital, was achieved. Theme 1, described the challenges that restricted participation. Theme 2, presented the facilitators that enhanced functional tasks and lastly, theme 3 described the participants adaptation process to reintegrate into the community.

CHAPTER FIVE

Discussion

5.1 Introduction

This chapter presents the main findings of the study. The aim of the study was to explore and describe the perspectives and experiences of stroke survivors' community reintegration after receiving inpatient occupational therapy intervention at a district hospital. The aim and the objectives of the study will be discussed and supported with latest literature on community reintegration of stroke survivors. Furthermore, in this chapter, the researcher will elaborate on how the participants experienced community reintegration after receiving occupational therapy intervention. The challenges they faced, the facilitators they experienced during community reintegration as well as how they addressed the adaptation strategies to reintegrate into the community will be presented. Finally, there will be a discussion on the integration of the theoretical framework, namely the Model of Occupational Adaptation in providing a comprehensive understanding of the stroke survivors' perspectives of community reintegration at a district hospital in the Western Cape after occupational therapy intervention.

5.2 Barriers Experienced by the Stroke Survivor in Reintegrating to the Community

The term barriers used in this context refers to the challenges and participation limitations in daily tasks. Barriers referred in theme 1 can be defined as the factors that are absent or present in an environment of an individual that limits functioning (World Health Organization, 2011). In theme 1 the participants experienced challenges within the environment as well as resource limitation. Theme 1 represents the environment barriers within the Occupational Adaptation Model that limits the stroke survivor to reintegrate into the community.

5.2.1 Environmental barriers related to reintegration into the community

Environmental barriers in this context refers to the external factors which the participant is unable to control and that limited the participant to reintegrate into the community.

5.2.1.1 Lack of access to transport

All the participants in this study experienced barriers to access transport and travel within their community. A lack of accessibility to transport is seen as one of the major barriers for people with disabilities (World Health Organization, 2011). Accessibility to transportation for people with disabilities is seen as a major challenge as persons with disabilities are often unable to access health or rehabilitation services (Hussey et al., 2016). A study in Malawi commented that mini-bus taxis in Malawi are not wheelchair friendly even though they are more accessible than larger busses (Venter et al., 2002). Participants in the current study explained that they did not make use of public transport as taxi drivers had poor awareness of people with disabilities, and that they did not feel safe using taxis. This is in line with the study in Malawi where people with disabilities reported that the driving behaviour of mini-bus taxis is a major barrier, as they do not provide sufficient time for people to board the bus, thus making people with disabilities feel unsafe. According to the World Report on Disability, it is important for governments to ensure continuity of accessibility in transport. It further states that training should be provided to transport staff, together with reduced fees for people with disabilities (World Health Organization, 2011).

A study in Cape Town, South Africa, found that transportation was the main problem in accessing medical services for 72% of people with disabilities (Maart & Jelsma, 2014). The lack of accessible transport results in a reduced attendance rate for follow-up appointments (De La Cornillère, 2007). Within the current study, participants experienced an inability to use transport within the community and were also unable to make use of their own private

transportation. This result is in line with the findings of Heikkilä et al. (1999) where stroke clients' inability to drive their own car was about 60%. It was confirmed by one key informant that follow-up post discharge is limited due to transportation barriers. This validated the findings of previous studies where patients with disabilities experienced transportation limitations resulting in poor follow up to medical services.

5.2.1.2 Mobility limitations in the community

According to the participants, they experienced limitations with regards to their ability to mobilise. Participants expressed a fear of falling, the inability to get in and out of a vehicle and even the inability to access important community centres like churches and shopping malls. Community mobility can be defined as the ability to move oneself within one's own community including the ability to drive or use public or private transport (Pendleton & Schultz-Krohn, 2006).

According to Hackett et al. (2000) stroke survivors also have problems with the ability to walk outside. Another study in New Zealand noted that people who had suffered a stroke were reported to have major community ambulation challenges (Lord et al., 2008). It was highlighted in the current study that stroke survivors also had difficulty mobilising within the community. One participant stated that he only experienced difficulty with mobility in the initial stage, one found it difficult navigating stairs, while only one other participant stated that she was mostly bedbound. Two other participants expressed the inability to get in and out of various vehicles. This study concurs with the findings of Venter et al. (2002), as participants expressed inability to mobilise over uneven surfaces. The study further states that the driving behaviour of drivers of public transport is another barrier for people with disabilities, as drivers have a lack of awareness and training in assisting people with disabilities to board and alight busses safely.

The world disability report emphasises that to ensure accessibility to people with disabilities it is important to improve pedestrian crossings, pavements and ramps so that people with disabilities can mobilise safely within the community (World Health Organization, 2011).

5.2.1.3 The unforeseen impact of the Covid-19 pandemic on occupational therapy intervention

The Covid-19 pandemic had an impact on a broad spectrum of people globally. Research is still limited on the long-term effects this pandemic has had on stroke rehabilitation (D'Anna et al., 2021). According to a study done in Madrid, it was found that stroke rehabilitation was significantly affected during the pandemic with delayed therapeutic intervention during the acute phase, as well as reduced rehabilitation bed and early discharges without completing the full rehabilitation programme, in order to protect patients and staff from becoming infected (Fuentes et al., 2020). It is evident that the pandemic had an impact on the participants from this study. Participants stated that they were unable to attend group therapy, that families were involved in therapy until hospital policy changed, and that family members were not allowed to accompany patients to treatment sessions. Key informants stated that they had limited or no family trainings. When possible only one family training was provided on the day of discharge, or telephonic training was provided. This contradicts the stroke guideline that stroke survivors require family meetings and training prior to being discharged from hospital (Bryer et al., 2010). During the global lock-down protocols, telerehabilitation was implemented. Telerehabilitation refers to the alternative care of inpatients who are discharged early after the acute phase to reduce the length of hospitalisation. Telerehabilitation is a treatment intervention of the acute phase, substituting the face-to-face in-person approach by making use of technology (Carey et al., 2007). The COVID-19 pandemic necessitated the use of telerehabilitation to limit in-person rehabilitation to prevent secondary complications and to

render rehabilitation feasible during lockdown periods (Iodice et al., 2021); however, it is important to note that patients frequently also require access to various technological devices.

5.2.2 Challenges experienced due to limited resources

Limited resources as discussed in theme 1 are seen as limited therapeutic services, poor family involvement, financial constraints and poor availability of adaptive equipment.

5.2.2.1 Poor holistic approach and limited therapeutic resources impacts therapeutic services

Participants felt that while they were still receiving therapy in hospital the MDT did not communicate with one another, resulting in premature discharges. This statement is confirmed by one of the key informants who stated that the hospital lacked a holistic approach and that OTs received patient referrals late or patients were being discharged without the knowledge of the therapist. According to the South African stroke guideline stroke patients should be assessed fully in 24 hours of onset of the stroke by each team member, and family meetings should be held within the first week of therapy (Bryer et al., 2010). Unfortunately according to the key informant this was not always the case. The premature discharge had an impact on the participants' discharge process as not all therapeutic goals were met, and family training was not provided. This is confirmed in previous literature as delayed referrals remains a major obstacle and a hospital stay of six weeks increases the probability of improved function prior to discharge (Mamabolo et al., 2009; Morrison et al., 2008). Another participant commented that they had to wait a long time to start with outpatient therapy. Both key informants commented on the fact that there was a shortage of therapeutic resources. They said that they experienced a high patient load and that it directly impacted the quality of services delivered. Another obstacle they experienced was the lack of therapists within the community. Patients have to be referred to clinics within their catchment area, however some clinics did not provide therapeutic services and these patients then need to be followed up at the district hospital,

adding to their already high patient load. A study conducted in Canada found that an inadequate budget allocated to rehabilitation services resulted in limited rehabilitation staff (Camden et al., 2010). Camden et al. (2010) reported that the inadequate ratio of rehabilitation staff compared to the number of patients, resulted in delayed rehabilitation service delivery. This is also true in the Western Cape where limited inpatient rehabilitation services and a lack of staff in facilities result in patients being discharged back into the community and thus they continue to experience limitations within their daily life (Kloppers et al., 2016; Kumurenzi et al., 2015). These findings are supported by Hall and Taylor (2003) who found that limited fund allocations negatively affect the quality the rehabilitation staff offer.

5.2.2.2 Poor family education/involvement impacts community reintegration

The findings in the study show that participants felt that their caregivers were unprepared to take care of them once they returned home. Previous literature confirms this statement as stroke patients in the Western Cape received minimum information on further rehabilitation once they were discharged back into their community (Kloppers et al., 2016). Key informants argued that due to lack of social support, patients found it difficult to integrate back into the community. Participants in the current study agreed that they experienced a lack of social support from their families, however they felt that this was due to the fact that their family members were not prepared for the new adapted life at home, and that they did not know how to manage them. It can be argued that the poor social support is directly affected by limited healthcare input after discharge, and that caregivers may find it challenging to adapt to a new lifestyle as they do not understand the gravity of taking care of a stroke survivor (Rouillard et al., 2012).

According to the guideline developed by Bryer et al. (2010) it is important to reduce the burden of care, and training of caregivers should be addressed by the rehabilitation team. Participants

in the current study acknowledged that family members were not consulted, and they felt that even telephonic communication would have been advantageous. The guideline further states that a formalised family meeting should be held ideally within the first week of therapy, and the aim should focus on education. Even prior to the discharge of patients, families should have the opportunity to have a trial period at home to assess and address unforeseen problems before the final discharge. Studies in South Africa confirm that families received poor family training and that stroke survivors experienced limitations when returning home; thus stroke survivors and their caregivers had poor insight into their condition (Govender et al., 2019). Key informants stated that family members did not realise the gravity of taking care of a stroke survivor, and the participants agreed with this statement but argued that the family was not educated by the rehabilitation team.

5.2.2.3 Accessibility to therapy is a financial strain

The accessibility to healthcare in South Africa is a major concern as seen in previous studies. The financial impact involved in accessing these healthcare services is another great concern. In the current study participants expressed that the lack of financial resources makes it difficult for them to travel from their homes to access therapy. In Ghana it was found that distance and the number of people with disabilities have to pay to access healthcare centres have a direct impact on the healthcare utilisation (Badu et al., 2015). In a peri-urban area of South Africa it was found that 5% of a family's income is consumed for one return trip for rehabilitation services at a hospital that is 30 km away (Saloojee et al., 2007). In Cape Town, poor attendance was directly related to poor attendance of follow-up treatments (Whitelaw et al., 1994). These findings concur with the findings of the current study, as participants and key informants mentioned that the financial impact is great when they need to access healthcare services. It can be argued that the lack of affordable transportation could have an impact on decreased

community reintegration, as stroke survivors are not able to afford further rehabilitation. Home-based rehabilitation programmes could potentially be considered as patients' satisfaction with these services are generally higher and this could potentially improve rehabilitation outcomes as stroke survivors will not miss important therapeutic interventions (Lee et al., 2011).

5.2.2.4 Limited availability of equipment

Stroke survivors experience difficulty in executing different tasks and activities in their lives after being discharged from hospital (Kersten et al., 2002). This is confirmed by the WHO (2011) that the unmet need to have assistive devices can result in poor outcomes for people with disabilities, with decreased and limited activity participation and reduced quality of life. Participants in the current study expressed dependence when executing Basic ADL and Instrumental ADL tasks. Basic ADLs can be defined as “tasks that include self-care, functional mobility, sexual activity and sleep/rest”, while Instrumental ADLs can be defined as “tasks that include community device use, health management and maintenance, financial management, meal preparation and clean-up and community mobility” (Pendleton & Schultz-Krohn, 2006, p. 147). Many stroke patients require assistive devices, adaptive equipment or mobility aids including wheelchairs to perform ADL tasks. There is a lot of adaptive equipment available to promote functioning. These include but are not limited to eating utensils, build up grips, adapted knives, plate guards, long-handled sponges, button hooks and build-up toilet seats. In a meta-analysis it was found that OT increased ADL independence by using adaptive equipment (Legg et al., 2006).

In this study participants experienced dependence in both BADL and IADL tasks. This contradicts the findings of (Hartman-Maeir et al., 2007). Hartman-Maeir found that one-year

post-stroke, patients experienced more dependence in instrumental activities of daily living compared to basic activities of daily living. Most participants in the current study expressed dependence in dressing, these included donning shoes and socks, and manipulating buttons. Furthermore, they expressed that they no longer wear the clothing as they did pre-morbidly as they are unable to dress themselves independently. Another participant felt embarrassed to inform the occupational therapist that she struggles with her shoelaces. Two participants were able to perform dressing tasks as they were educated on adaptive techniques to perform these tasks. One key informant in the current study agreed that stroke survivors are experiencing limitations with ADL tasks post discharge. The key informant stated that more equipment resources could potentially benefit stroke survivors to improve functional outcomes. The key informant further stated that due to resource constraints for adaptive equipment they were unable to issue important items to assist with function. The current study confirms what Blonder et al. (2007) found as participants in the current study also experienced limitations with food preparation and cleaning. Participants were unable to prepare their own meals and had to rely on caregivers to perform these tasks. Particular problems and limitations to complete IADL activities especially household tasks like cooking and childcare were experienced especially by women (Blonder et al., 2007). According to Koch et al. (2005) stroke survivors were failing to perform tasks like driving, housework and the ability to manage finances. Even though participants in the current study faced problems with household tasks like cleaning, they did not mention difficulty managing their finances (Koch et al., 2005). According to the World Report on Disabilities it was found that in four Southern African countries only 17-37% of people with disabilities received the assistive devices they required (World Health Organization, 2011).

5.3 Facilitators that Promote Participation of Stroke Survivors during Community Reintegration

In theme 2 the facilitators that emerged in the study included the supportive systems of stroke participants, and the positive contribution that facilitated improved function. Facilitators can be described as the factors that can improve functioning and reduce disability within a person's environment. These include a physical environment, assistive technology, positive attitudes of people, services or policies that enhance participation (World Health Organization, 2004). Theme 2 represents the interaction between the person and the environment to create an adaptive response within the Occupational Adaptation Model.

5.3.1 Various systems that facilitate rehabilitation post stroke

The importance of family support and the therapeutic assistance of the treating therapist had a positive outcome on community reintegration as mentioned in theme 2.

5.3.1.1 The importance of involving family during therapeutic intervention

The participants in the current study related positive responses towards their family members understanding their condition. They reported that family members were able to assist them with various ADL tasks. This is in contrast to the findings of Govender et al. (2019), that stroke survivors experienced stigmatisation from friends and family and this left them feeling socially isolated as they were unable to resume previous activities. One key informant stated that social support was inadequate, contradicting most participants' statements on support they had received from family and friends. Contrary to previous literature, the participants in this study did not report negative associated feelings towards family. In a previous study it was found that support and interaction with people in the community contributed to feeling socially disconnected (Rittman et al., 2007). Another study that looked at family involvement found that stress and frustration had been reported by family members during the transition from

hospital into the community (Hare et al., 2006). This may indicate that community awareness and education had an impact on how they treated stroke survivors in the community.

5.3.1.2 Satisfaction towards occupational therapists and therapeutic services received

This study revealed the value and impact the occupational therapist had with the participants of the study. A study by Chimatiro (2012) found that stroke survivors had multiple factors that facilitated reintegration into the community, these included support from family and friends, religious factors, the fact that they had transport, financial income and health insurance. A study that was conducted in Bishop Lavis, Western Cape, suggested that participants who attended a community rehabilitation centre experienced satisfaction with the services they received. Community rehabilitation refers to a high-intensity rehabilitation services and caters for individual rehabilitation needs (Western Cape Department of Health, 2011). The study commented on positive experiences with service delivery reported by participants (Kloppers et al., 2016). In line with the current findings participants from this study were satisfied with the services they received from the occupational therapy department. The participants not only commented on the improved functional improvement they experienced, but they also commented on the affirming interpersonal relationship between the therapist and patient. This positive outlook on occupational therapy may provide an improved compliance to therapy and decreased dependability in order to enhance community reintegration.

5.3.2 Contributions that facilitated function

The factors that had a positive contribution in theme 2 included community reintegration, and in this context it is seen as the importance of mobility equipment and the issuing of home exercise programmes.

5.3.2.1 The availability of mobility equipment enhanced function

A stroke can have an impact on an individual's ability to walk and can have an effect on gait impairments like an unstable, inefficient walking pattern and the risk of falls. Mobilising within the community has been a major barrier for stroke patients (Lord et al., 2008). At least half of all stroke patients require an assistive device to assist with their mobilisation, most frequently a crutch or a cane (Jutai et al., 2007). The immediate benefits of various assistive devices have shown that mobilisation was improved with the use of a cane or crutch after a stroke (Laufer, 2002). Stroke patients reflected that their walking, walking confidence and walking safety improved once they started using an assistive device (Tyson & Rogerson, 2009). Individuals who are unable to mobilise safely and independently with an assistive device, can make use of a wheelchair to enhance their mobility. Up to about 40% of stroke patients use a wheelchair at discharge post rehabilitation (Mountain et al., 2010).

In the current study participants said that they experienced improved function in mobility by making use of various mobility equipment. These assistive devices included wheelchairs, crutches, walking frames and AFOs. The participants had positive emotions when expressing their ability to return to walking. One participant stated that without the assistive device he would not have been able to manage his daily tasks. This confirms the finding above that various assistive devices benefit the stroke patients to return to the community, as participants were able to resume tasks like attending church.

5.3.2.2 Home exercise programmes improved function

Participants conveyed the positive impact that home exercise programmes had on their function once they returned home. As previously mentioned, the Covid-19 pandemic had a considerable impact on therapeutic services and therapists had to put alternative methods in place for a continuation of therapy. A randomised control trial found that stroke patients had improved

functionality of their upper limbs, lower limbs, ADLs and functional independence when provided with a home exercise rehabilitation programme (Saadatnia et al., 2020). Another study confirms that this approach is more feasible and safer while barriers like transportation, costs, and caregiver burden could be eliminated especially in low-income countries (Erler et al., 2019). A study conducted in the United states of America described the current OT practices in the usage and prescription of Home Exercise Programs (Proffitt, 2016). The study found that even though HEP are prescribed frequently by OTs, little is known about the content, dosage and clinical reasoning, and that clinical practice guidelines contain limited evidence to support the use of HEP (Proffitt, 2016).

5.4 Stroke Survivors Adapted Strategies to Reintegrate into the Community

The participants used internal and external adaptation strategies to reintegrate into the community. Theme 3 corresponds towards the adaptive response the stroke survivors had to reintegrate back into the community.

5.4.1 Internal adaptation strategies

The internal adaptation as illustrated in theme 3 is an internal process to overcome the barriers a participant had experienced.

5.4.1.1 Improved insight resulted in an improved functional outcome

In the current study participants expressed that they gained insight and received most information from the treating therapist. The participants reported that within the initial phase of therapy they did not see the benefits of continuing with therapy; however, as time went by, they started seeing improved functional results. One participant mentioned that the OT helped her to gain knowledge on her diagnosis and the effect it had on her body and function. One participant stated that he is a medical doctor and required evidence-based therapeutic

interventions. The participant further stated that he started seeing positive results as his hand function improved, thus empowering the participants to continue with rehabilitation and finally seeing functional improvement. The participants reported that the treating therapist also helped improve their insight into their condition and provided them with exercises that they needed to continue with at home for improved functional outcomes. The findings in this study are similar to the findings from a study conducted at a rehabilitation centre in the Western Cape, South Africa, (Kloppers et al., 2016). Kloppers et al. (2016) found that gaining insight into their own condition prevents disability and empowers patients to make informed decisions regarding their own care. Through education, participants gained knowledge about how to engage in functional tasks after their diagnosis and this resulted in improved health. The findings in this study and those of Kloppers et al. (2016) are contrary to those found by Darrah et al. (2002). Darrah et al. (2002) noted that patients reported that they were misinformed and lacked knowledge regarding their disabilities.

5.4.1.2 The importance of confidence on functional outcomes

Participants in the current study expressed that confidence in their own abilities improved after receiving occupational therapy. Limited literature is available on how the stroke survivor's confidence is affected and how it could be improved. Bandura (as cited in Horne et al., 2014, p.1125-1126) defines confidence as a person's own ability to master the things they attempt or try or do. Stroke survivors experience psychological distress including a decrease in confidence (Stone, 2004). Lower levels of confidence may have an impact on a person's independence or lead to poor health-related factors (Braun & Clarke, 2006; Doyle, 2002; Ellis-Hill & Horn, 2000). Contrary to these findings the participants in this study maintained that the OT improved their confidence through positive verbal reinforcements during their therapeutic sessions and that the OT encouraged independence and self-confidence by continuously encouraging the

participant to attempt self-care tasks independently. Thus, confirming that positive reinforcements facilitated rehabilitation and community reintegration, as participants stated that they were able to resume daily functions like self-care tasks, attend religious gatherings and even return to work-related tasks like working on a computer. The current study supports the findings of Horne et al. (2014) that confidence is the successful engagement in everyday activities with positive reinforcements from others.

5.4.2 External adaptative factors that facilitated community reintegration

In theme 3 the external process of adaptation is facilitated by the availability and use of valuable community resources and the adaptive techniques learnt in therapy.

5.4.2.1 Value of community resources to the stroke survivor

In this study participants and key informants mentioned that community resources are of utmost benefit to not only the patient but family members as well. Participants mentioned that the OT made referrals to various institutions that aided their functional outcomes; however, due to unforeseen circumstances some of these institutions were closed. These facilities included step down and work training programmes. The participant further stated that without these referrals she would not have been able to drive her own car again. Unfortunately, the referral to one of the resources was within the private sector, and as mentioned earlier in the study most participants have financial restraints and could not afford private resources driving assessments.

Both key informants stated that intermediate care facilities are limited once being discharged from hospital. Intermediate care ensures a successful discharge back into the community setting or other environments like old age home or institutions (Western Cape Department of Health, 2011). The majority of patients admitted to intermediate care facilities had suffered a stroke

and first received inpatient rehabilitation at a hospital. This referral was seen as a method to continue with stroke care (Mabunda et al., 2017). The lack of intermediate care facilities post stroke may lead to reintegration issues. The limited rehabilitation services as perceived by the key informants is in line with the report by the World Health Organization (2011) that mainly low-middle-income countries struggle to financially support rehabilitation services. Furthermore, the intermediate care facility in the Western Cape had a hospital bed utilisation rate of 94% in 2011. This facility had a limited bed capacity of 106-beds with a 105 beds consistently occupied (Mabunda et al., 2017). It is concerning to note the limited available resources of intermediate care facilities and capacity post discharge from hospital. However in line with the current study Mabunda et al. (2017) found a high patient satisfaction rate with the care they received from the intermediate care facility, adding to the value of community resources.

In line with the Road to Wellness 2030 vision, the Western Cape Department of Health is expanding the community services by providing Rehabilitation Care Workers (RCWs) as an additional form of support to patients on the home-based care and intermediate care platform (Western Cape Department of Health, 2014). This service will be supported by a range of therapists while the more complex patients requiring specialised rehabilitation will be referred to the intermediate care facility available in the province. The implementation of the RCWs services may add value and have a positive outcome on the stroke patients' community reintegration due to improved accessibility and availability of community resources post stroke.

5.4.2.2 New adapted techniques learned in therapy resulted in improved function

Most participants in the current study expressed that they had a positive outcome in functional tasks post OT intervention. OT interventions include re-education of physical functioning, improvement of ADL tasks, perception, cognition, home visits, social and leisure activities, education and the provision of assistive devices and equipment (De Wit et al., 2006). OT services significantly improve patients ability to perform ADL activities (Walker et al., 1999). The findings of this study concur with the findings from Kumurenzi et al. (2015), as stroke patients revealed that the service providers knew what they were doing during treatment sessions by providing them with the best techniques to improve function. Participants expressed that knowledge regarding adaptations improved ADL function and reduced the burden on their family and that the therapists focussed on improving and broadening their skills. The participants further stated that they would not have been able to perform their daily ADL tasks without the assistance of the therapists. This validated the findings of a study completed in the Western Cape that participants felt that rehabilitation helped them with independence in their ADLs through improved knowledge and skills (Kloppers et al., 2016).

5.5 Summary

In this chapter the researcher discussed the results of the study in relation to the research question. The experiences of stroke survivors on community reintegration after receiving inpatient occupational therapy intervention at a district hospital were noted and the results compared to the current available literature. The participants expressed their experiences on the challenges related to participation within the environment and limited resources. They further expressed their perspectives on facilitators that enhanced functional tasks and the adaptation strategies utilised to reintegrate back into the community.

CHAPTER SIX

Conclusion and Recommendations

6.1 Conclusion

The aim of the study was to explore and describe the perspectives and experiences of stroke survivors' community reintegration after receiving inpatient occupational therapy intervention at a district hospital. Three themes emerged from this study: (i) stroke survivors' challenges related to participation in functional tasks or occupations, (ii) stroke survivors' facilitators related to participation in functional tasks or occupations, and (iii) adaptation strategies utilised by stroke survivors to reintegrate back to their homes and the communities.

According to the findings of the current study the participants experienced barriers post discharge from a district hospital in the Western Cape. The study displayed barriers at an environmental level as well as a resource level. The lack of access to transportation for people with disabilities has been identified as one of the key barriers to reintegrate back into the community. Transportation limitations stretch further to the inability to reach healthcare services and follow-up appointments, resulting in poor adherence to therapy and ultimately poor functional outcomes. The study also found that participants experienced financial restraints to access healthcare centres to attend and continue with rehabilitation post discharge.

The current study found that participants experienced difficulty to mobilise within their own community including the inability to drive or get in and out of public and private transport. This resulted in the inability to access community centres like attending religious gatherings and shopping centres. The long-term impact of the COVID-19 pandemic on stroke patients presents challenges to individuals receiving rehabilitation, however due to restrictions put in place by government to curb the spread of the virus, participants in this study expressed that therapy intervention was limited by minimal or no family training, early discharge from

rehabilitation programmes, and poor follow-up sessions post discharge from rehabilitation programmes. The current study found poor MDT communication and the premature discharge of stroke survivors that resulted in no follow-up referrals, no family training and limited therapeutic input due to late referrals to the OT department. These outcomes may also be due to the limited availability of staff in the hospital due to the high demand of patients per available therapist. As mentioned earlier the study found that families were not prepared prior to discharge from hospital. Key informants and participants confirmed this statement. Feeling unprepared to take care of the person with disability added to the already heavy burden these family members experienced. In this study it was found that participants experienced limitations in performing IADL tasks, including cooking and cleaning. The participants in the study did not receive any assistive devices to improve these functions prior to discharge. It was found that the OT department was unable to issue these devices due to limitations in budget allocations.

The study underscored the importance of family support during rehabilitation. Involving family members in rehabilitation is of outmost importance as some families of stroke survivors struggled with accessing rehabilitation programmes due to financial challenges during the pandemic. The study also found that the participants' perceptions of their therapists were positive and satisfactory. A positive interpersonal relationship between patient and therapist resulted in trust and improved compliance. Even though the study found limitations with regards to issuing assistive devices it was found that participants in this study received adequate mobility devices like walking frames AFOs and wheelchairs, and thus experienced improved mobilisation. The study found that even though participants experienced limited follow-up appointments and limitations in accessing healthcare services, the home exercise programmes issued by the OT improved their functional outcomes. These programmes were specifically formulated for each individual to improve function.

Improved insight was found to be a positive adaptation strategy to improve function. Once the participants understood their own body and functions, this empowered them to continue with rehabilitation and finally see improved functional results. The improved insight allowed them to understand the home exercises they were provided with as mentioned earlier. By feeling empowered with the knowledge gained the participants' confidence was improved and this resulted in them continuing with therapy not only in a healthcare setting but also at home. The study findings indicated that the OT contributed to the improved confidence among the stroke survivors through positive reinforcement and by encouraging independence.

The study found that community resources like intermediate care facilities and community therapy is of utmost importance to gain independence post discharge. However, it was found that not all stroke survivors received intermediate care post discharge due to the limited availability of these facilities. Post discharge patients are either discharged back into the community with the possibility of outpatient treatment or they may be referred to an intermediate care facility. Unfortunately, not all healthcare clinics have therapeutic services, resulting in poor compliance towards therapy due to the fact that patients or clients had transportation issues to access therapy that was not within their catchment area. However, it was found that participants had positive experiences with intermediate care facilities that resulted in improved function and community reintegration. As mentioned earlier participants in this study stated that their experiences with the treating therapist was positive, and that the therapy aimed for specific improved functions. This was confirmed as the therapeutic interventions were aimed at learning new techniques in order to regain function and reintegrate back into their home environment.

6.2 Recommendations

The study showed that stroke patients experience difficulties in reintegrating back into the community due to environmental and resource constraints.

Recommendations for occupational therapy research: The impact of the pandemic on rehabilitation is still unclear. It is advised that in future the possibility and accessibility of teletherapy may be included in the public sector.

Recommendations for the department of health or policy development: The study found limited rehabilitation staff and limited assistive devices to aid independence within the district hospital as well as in the community. Based on these findings service providers could consider increasing the funding to rehabilitation organisations in order to increase the number of occupational therapists at the district hospital and community health centres, as this will promote improved family educational sessions and decrease the long waiting list that patients currently experience.

Recommendations for occupational therapy education: The researcher suggests that service providers address the ongoing challenges of accessibility of transport to healthcare centres within the Western Cape. Education and training may be provided for taxi drivers to make transport safer and more accessible to people with disability.

6.3 Limitations

Due to the COVID-19 pandemic, data collection was limited to mostly telephonic interviews as participants feared contact with the researcher. Only one interview was conducted face-to-face while 11 other interviews were conducted telephonically. The fact that the researcher was unable to meet the participants in person may have resulted in the participants not openly exchanging information as they would have done in a face-to-face interview.

Caution must be taken when generalising the findings of the study as qualitative research has context-specific information, and furthermore a limited sample size is not a representation of the larger population.

The fact that the district hospital only employs a few therapists, the key informants may have felt that if they provided negative information about the rehabilitation programmes at their places of employment, that the information could be traced back to them, even though the researcher assured anonymity in the report and or any publication of papers.



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INFORMATION SHEET

Project Title:
Stroke patients' perspective of community reintegration after receiving Occupational Therapy intervention at a District Hospital in the Western Cape, South Africa.

What is this study about?

This is a research project being conducted by Sunel-Marie Van der Westhuizen at the University of the Western Cape. The researcher is inviting you to participate in this research project because you have been diagnosed with a Stroke and received Occupational Therapy at Karl Berner Hospital. The purpose of this research project is to explore your personal experiences with regards to how you have reintegrated back into the community after receiving Occupational Therapy.

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

You will be asked to attend an interview with the researcher. The interview will take place at the Occupational therapy department at Karl Berner Hospital. The interview will be conducted only once. The interview could last from 30min to 60min. The questions that will be asked during the interview will relate to your opinion of reintegrating back into the community after receiving Occupational therapy. The interviewer may also ask your opinion on how to improve the Occupational therapy services to improve community reintegration.

Would my participation in this study be kept confidential?

The researcher undertake to protect your identity and the nature of your contribution. To ensure your anonymity, your personal information will be protected and that all interviews will be anonymous. Your name will not be recorded in the interview, or other collected data. A code will be placed on the survey and other collected data. Through the use of an identification key, the researcher will be able to link your survey to your identity, and only the researcher will have access to the identification key. To ensure your confidentiality, all information will be kept safe in locked filing cabinets, using identification codes only on data forms, and using password-protected computer files. If the researcher write a report or article about this research project, your identity will be protected. In accordance with legal requirements and/or professional standards, the researcher will disclose to the appropriate individuals and/or authorities information that comes to her attention concerning neglect or potential harm to you or others. In this event, the researcher will inform you that she have to break confidentiality to fulfil her 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 self 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 or counsellor for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about how we as Occupational Therapist can adapt our understanding of community reintegration and assist with a more client centred approach in therapy. 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 Sunel-Marie Van Der Westhuizen at the University of the Western Cape. If you have any questions about the research study itself, please contact Sunel-Marie at: 0723844469 Unit 780 De Veld, Somerset West, sunel2014@gmail.com. Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee.

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e-mail: research-ethics@uwc.ac.za

Xhosa translation if required

Oluqaphanda lupasivise sisisiqepheba sekomiti yophaphanda l'yunivesithi yaseNtshona Koloni kunye nekomiti yezeminqwano Biomedical.

Appendices

Appendix 1: Information Letter/Sheet



UNIVERSITY *of the*
WESTERN CAPE

Appendix 2: Consent Form



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
 Tel: +27 21-959-2390 Fax: 27 21-959-3404

Researcher: S. Van der Westhuizen
 Contact: 0723844469
 Email: sunelot2014@gmail.com
 Student number: 4010509

CONSENT FORM

Title of Research Project: Stroke patients' perspective of community reintegration after receiving Occupational Therapy intervention at a District Hospital 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.....

Biomedical Research Ethics Committee
 University of the Western Cape
 Private Bag X17
 Bellville
 7535
 Tel: 021 959 4111
 E-mail: research-ethics@uwc.ac.za

Appendix 3: Interview Schedule: Stroke Survivors



UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959-2900 Fax: 27 21-959-5404

Researcher: S. Van der Westhuizen

Contact: 0723844469

Email: sunele2014@gmail.com

Student number: 4010509

INTERVIEW SCHEDULE: Stroke participants

Title of Research Project:

Stroke patients' perspective of community reintegration after receiving Occupational Therapy intervention at a District Hospital in the Western Cape, South Africa

Objective of study:

1. To explore the stroke survivors' perspective and experiences of barriers when reintegrating into the community after completing in patient occupational therapy intervention
2. To explore the stroke survivors' perspective and experiences of facilitators when reintegrating into the community after completing in patient occupational therapy intervention
3. To explore the stroke survivors' perspective and experiences of adaptive strategies used when reintegrating into their occupational roles in the community
4. To explore the strategies to enhance the ability of stroke survivors to reintegrate into the community

Name of Interviewer:

Place of interview:

Date of interview:

Background of participant



UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959-2900 Fax: 27 21-959-5404

Researcher: S. Van der Westhuizen

Contact: 0723844469

Email: sunele2014@gmail.com

Student number: 4010509

Gender:

Age:

Questions

1. Please describe to me your experiences of returning back home after receiving Occupational Therapy at Karl Bremer Hospital.
 - a. Probe: Was there any difficulties that you experienced?
 - b. Probe: Was there any thing (example person or organisation) that helped you?
2. What do you think were the benefits of Occupational Therapy prior to returning home after you had the strokes?
 - a. Probe: Was there anything specific during your Occupational Therapy sessions that helped you to function better at home?
 - b. Probe: Was there any advice or equipment that assisted you to return home that you received?
3. What did you feel restricted you or made it difficult to return to a previous way of living?
 - a. Probe: Was there any restrictions that you are aware of now, that you would have raised whilst in hospital or prior to returning home?
4. What adaptations did you have to make to your life to continue your life after returning to your community?
 - a. Probe: Can you describe the adaptations when you returned to work?
 - b. Probe: Can you describe the adaptation when participating in leisure or sport activities, (example church, soccer, socialising with friends or family)
 - c. In your opinion how did your adapt to life after a stroke.
5. What would you feel may the Occupational Therapy Department include or change to assist stroke survivors with an improved community integration.
6. Is there any other things you would like to share with me in relation to returning home after a stroke.

Appendix 4: Interview Schedule: Key Informants



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959-2390 Fax: 27 21-959-3404

Researcher: S. Van der Westhuizen

Contact: 0723844469

Email: sunald2014@gmail.com

Student number: 4010509

INTERVIEW SCHEDULE: Key Informants

Title of Research Project:

Stroke patients' perspective of community reintegration after receiving Occupational Therapy intervention at a District Hospital in the Western Cape, South Africa

Objective of study:

1. To explore the stroke survivors' perspective and experiences of barriers when reintegrating into the community after completing in patient occupational therapy intervention
2. To explore the stroke survivors' perspective and experiences of facilitators when reintegrating into the community after completing in patient occupational therapy intervention
3. To explore the stroke survivors' perspective and experiences of adaptive strategies used when reintegrating into their occupational roles in the community
4. To explore the strategies to enhance the ability of stroke survivors to reintegrate into the community

Name of Interviewer:

Place of interview:

Date of interview:

Background of participant



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959-2390 Fax: 27 21-959-3404

Researcher: S. Van der Westhuizen

Contact: 0723844469

Email: sunald2014@gmail.com

Student number: 4010509

Gender:

Age:

Questions:

1. Please describe to me the difficulties that stroke survivors experience when returning home from hospital?
 - a. Probe: For example- Physical, emotional or environmental limitations.
 - b. Probe: What do you think is the main limitations of a stroke survivors after being discharged from Karl Bremer Hospital?
2. What adaptations do you feel stroke survivors have to make in their life after returning home?
 - a. Probe: What would you prioritise as the main focus of rehabilitation for stroke survivors prior to being discharged from Karl Bremer Hospital?
 3. In your opinion how do think that the Occupational Therapy department could improve on its processes in order to enhance the community' reintegration of stroke survivors?
 - a. Probe: What should the focus of intervention be, to facilitate enhanced community reintegration?
 - b. Probe: Can you suggest alternative interventions the Occupational Therapy department should focus to improve community reintegration.
4. Please describe whether stroke survivors receive optimal intervention, and if not, what can be done in your opinion to improve the optimization of the services.
 - a. Probe: Please describe whether there are any other suggestions to improve the occupational therapy stroke rehab intervention,?
 - b. Probe: What resources are needed in order to enhance the intervention process

Appendix 5: Information Sheet



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2390 Fax: 27 21 959 3404

Researcher: S Van der Westhuizen
Contact: 0723844469
Email: sunelo2014@gmail.com
Student number: 4010509

INFORMATION SHEET

Project Title:

Stroke patients' perspective of community reintegration after receiving Occupational Therapy intervention at a District Hospital in the Western Cape, South Africa.

What is this study about?

This is a research project being conducted by Sunele-Marie Van der Westhuizen at the University of the Western Cape. The researcher is inviting you to participate in this research project because you work at Karl Bremer Hospital as either a Occupational Therapist or Physio Therapist. The purpose of this research project is to explore how you perceive stroke survivors reintegration back into the community after receiving Occupational Therapy.

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

You will be asked to attend an interview with the researcher. The interview will take place at the Occupational therapy department at Karl Bremer Hospital. The interview will be conducted only once. The interview could last from 30min to 60min. The questions that will be asked during the interview will relate to your opinion stroke survivors reintegration back into the community after receiving Occupational therapy. The interviewer may also ask your opinion on how to improve the Occupational therapy services to improve community reintegration.

Would my participation in this study be kept confidential?

The researcher undertake to protect your identity and the nature of your contribution. To ensure your anonymity, your personal information will be protected and that all interviews will be anonymous. Your name will not be recorded in the interview, or other collected data. A code will be placed on the survey and other collected data. Through the use of an identification key, the researcher will be able to link your survey to your identity, and only the researcher will have access to the identification key. To ensure your confidentiality, all information will be kept safe in locked filing cabinets, using identification codes only on data forms, and using password-protected computer files.

If the researcher write a report or article about this research project, your identity will be protected. In accordance with legal requirements and/or professional standards, the researcher will disclose to the appropriate individuals and/or authorities information that comes to her attention concerning neglect or potential harm to you or others. In this event, the researcher will inform you that she have to break confidentiality to fulfil her 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 self 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 or counsellor for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about how we as Occupational Therapist can adapt our understanding of community reintegration and assist with a more client centred approach in therapy. 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 Sunele-Marie Van Der Westhuizen at the University of the Western Cape. If you have any questions about the research study itself, please contact Sunele-Marie at: 0723844469 Unit 780 De Valde, Somerset West, sunelo2014@gmail.com. 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:

Prof. Jo-Celeste De Jongh
Research Supervisor
University of the Western Cape
Private Bag X17
Bellville 7535
jdejongh@uwc.ac.za

Prof. Shaheed Soeker,
Research Co-Supervisor
University of the Western Cape
Private Bag X17
Bellville 7535
shsoeker@uwc.ac.za

This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee.

Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville
7535
Tel: 021 959 4111
e-mail: research-ethics@uwc.ac.za

Xhosa translation if required

Cuphambeka ngobomi besebenzisa isigqeba sekomiti yophando luyobesithi yasekushona Kodani kunye nekomiti yezeminyango Biomedical.

Afrikaans translation if required

Hierdie navorsing is goedgekeur deur die Universiteit van Wes-Kaapland se Biomediese Navorsingsetikekomitee.

Appendix 6: Ethics Reference Number



UNIVERSITY of the
WESTERN CAPE



13 October 2020

Mrs SM Van der Westhuizen
Occupational Therapy
Faculty of Community and Health Sciences

Ethics Reference Number: BM20/8/15

Project Title: Stroke patients' perspective of community reintegration after receiving Occupational Therapy intervention at a Secondary Hospital in the Western Cape, South Africa.

Approval Period: 13 October 2020 – 13 October 2023

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific 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 annually by 30 November for the duration of the project.

Permission to conduct the study must be submitted to BMREC for record-keeping.

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

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

Director: Research Development
University of the Western Cape
Private Bag X 17
Belville 7535
Republic of South Africa
Tel: +27 21 959 4111
Email: research-ethics@uwc.ac.za

NHREC Registration Number: BMREC-130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

Appendix 7: Approval Letter from Western Cape Government



STRATEGY & HEALTH SUPPORT

Health.Research@westerncape.gov.za
 tel: +27 21 483 0866; fax: +27 21 483 6058
 5th Floor, Norton Rose House., 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_202010_030
 ENQUIRIES: Dr Sabela Petros

**Private Bag X 17
 Bellville
 7535
 Republic of South Africa**

For attention: Mrs Sunel-Marie Van der Westhuizen

Re: Stroke patients' perspective of community reintegration after receiving Occupational Therapy intervention at a District Hospital in the Western Cape, South Africa.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

Karl Bremer Hospital	De Vries Basson	021 918 1205
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Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion date* which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY
 DIRECTOR: HEALTH IMPACT ASSESSMENT
 DATE: 14/01/2021
 CC