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Experiences and perceptions of stroke survivors and occupational therapists on community reintegration post stroke in the Western Cape

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EXPERIENCES AND PERCEPTIONS OF STROKE SURVIVORS AND OCCUPATIONAL THERAPISTS ON COMMUNITY REINTEGRATION POST STROKE IN THE WESTERN CAPE

Hendrina Cecilia Lindner

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.

Johannesburg

2022

DECLARATION

I, Hendrina Cecilia Lindner, hereby declare that this research report is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

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Signature:  Date: 16 June 2022

DEDICATION

To the stroke survivors I have had the privilege to work with. Your joy and motivation through all the difficulties you have experienced has encouraged me and challenged me. You have enriched my life.

ACKNOWLEDGMENTS

I would like to acknowledge and thank the following people for their continuous support and assistance during this study.

- My principal supervisor, Lebogang Maseko, for her support and academic guidance in writing this report.
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- My colleagues at Western Cape Rehabilitation centre, especially in Therapy 3, for granting me the opportunity to take time off to complete my studies, carrying my caseload and for all the encouragement and support along the way.
- The stroke survivor participants and occupational therapy participants that so willingly participated. For opening your homes and hearts to share your stories.
- My family and friends for bearing with me and sticking by my side through thick and thin.
- The Lord, my creator, for giving me this opportunity and providing me with the support network to carry me through.

ABSTRACT

Worldwide, stroke is one of the leading causes of death and disability. In South Africa, despite numerous policies guiding rehabilitation at different levels of care, stroke survivors show poor levels of community reintegration on returning home.

The purpose of this study was to explore the lived experiences of stroke survivors on returning home after having received in-patient rehabilitation as well as their perceptions of the barriers and facilitators to their recovery and process of community reintegration. Furthermore, the study explored the barriers and facilitators to facilitate community reintegration perceived by occupational therapists working in the same area when providing services for stroke survivors.

A descriptive, qualitative study design with a phenomenological emphasis was used to conduct this study. Demographic questionnaires and semi-structured key informant interviews were used to conduct interviews with eleven stroke survivors who had received in-patient rehabilitation and were one to three years post stroke as well as two occupational therapists servicing the same area.

Three themes emerged from the study. The first theme emerged as the changes in occupational performance experienced by stroke survivors. The second and third theme emerged as the barriers and facilitators to community reintegration as perceived and experienced by stroke survivors living in the Eastern Subdistrict of the Western Cape. Data from the occupational therapy participants were used to triangulate the data that emerged from the stroke survivor participant interviews.

Community reintegration continues to be a challenge for stroke survivors living in the Eastern Subdistrict of the Western Cape. Often the barriers are social determinants of health such as the environment, poor coordination of rehabilitation services and poor access to public transport. On the other hand, several facilitators such as stroke survivors' motivation, drive and social support systems were identified occupational therapists can capitalise on to facilitate the process of community reintegration for stroke survivors. The study highlighted the importance of effective discharge and community-based services to ensure the continuum of rehabilitation for stroke survivors when returning home.

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OPERATIONAL DEFINITIONS

Stroke	Stroke can be defined as a "neurological deficit attributed to an acute focal injury of the central nervous system (CNS), which occurs on a vascular basis. Stroke subtypes include ischaemic stroke/cerebral infarction, intracerebral haemorrhage (ICH) and subarachnoid haemorrhage (SAH)" (Taylor & Ntusi, 2019: 69).
Disability Adjusted Life Years	Disability Adjusted Years refer to the metric system used to calculate the morbidity and mortality linked to a disease (Maredza, Bertram & Tollman, 2015).
Rehabilitation	The World Health Organisation (WHO) defines *rehabilitation* as "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (World Health Organisation, 2020: viii).
Acute phase after a stroke	The acute phase after a stroke refers to the period of one to seven days after the onset of the lesion (Bernhardt et al., 2017).
Sub-Acute phase of stroke recovery	The sub-acute phase after a stroke consists of two phases. The early sub-acute period of recovery refers to 7 days to 3 months after a lesion. The late sub-acute refers to the second phase that last up to 6 months after the lesion (Bernhardt et al., 2017).
Chronic phase of stroke recovery	The chronic phase after a stroke refers the period after 6 months of a stroke and continues for the for the rest of the person's life (Bernhardt et al., 2017).
Community Reintegration	Community reintegration refers to the process whereby an individual resumes culturally and developmentally appropriate roles after a disability. It includes the ability "to engage in education, vocation, recreation, social interaction and community interaction...including independence in household activities, parenting, community mobility, vocational functioning, and development and maintenance of friendships and intimate relationships" (Sander, Clark & Pappadis, 2010: 121). For the purposes of this study and based on Landrum, Schmidt and McLean's (1995) rehabilitation outcome levels, community reintegration will not include productive activity such as formal employment.
Community-based Rehabilitation	Community-based rehabilitation (CBR) refers to an approach for community-based inclusive development that highlight the needs of persons with disabilities to be included in development initiatives (World Health Organisation, 2010).

ABBREVIATIONS

ADL	Activity of Daily Living
CBR	Community-Based Rehabilitation
CDC	Community Day Centre
CHC	Community Healthcare Centre
CHWs	Community Healthcare Workers
CRWs	Community Rehabilitation Workers
DoH	Department of Health
Eastern SD	Eastern Metro Health Subdistrict
ESD	Early Supported Discharge
FSDR	Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020
IADLs	Instrumental Activities of Daily Living
ICF	International Classification of Function
MDT	Multidisciplinary Team
NGTs	Nasogastric Tubes
NHI	National Health Insurance
OTPs	Occupational Therapy Participants
PEG	Percutaneous Endoscopic Gastrostomy
PEOP	Person-Environment-Occupation-Performance model
PHC	Primary Health Care
POPIA	Protection of Personal Information Act
PwD	Persons With Disabilities
QoL	Quality of Life
SSPs	Stroke Survivor Participants
UN	United Nations
UHC	Universal Health Coverage

WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION AND SCOPE OF THE RESEARCH REPORT

1.1 INTRODUCTION

Worldwide stroke is one of the leading causes of death and disability in adults and continues to increase in prevalence (Lozano et al., 2012; Maredza, Bertram & Tollman, 2015). In 2010, stroke was the second highest cause of mortality globally, accounting for 11.1% of the 52.8 million recorded deaths (Mukherjee & Patil, 2011). Of these global stroke related deaths, 85% occur in low- or middle-income countries (Mukherjee & Patil, 2011). A similar trend can be seen in South Africa, a middle-income country, where stroke ranks fourth as a leading cause of death, representing 5.1% of 456 612 registered mortalities (StatsSA, 2016). In the Western Cape, a province in South Africa, stroke also ranks as the fourth leading cause of death representing 5.6% of 48 141 annual registered deaths, with a slightly higher mortality and morbidity rate than the national average (Shisana et al., 2013; StatsSA, 2016). Despite the high mortality rate associated with stroke, with the advancements in stroke management, more people are surviving the acute stage (Mudzi, Stewart & Musenge, 2012; Bertram et al., 2013). As a result, more stroke survivors are being discharged from hospitals and returning home (Walsh et al., 2015) and require rehabilitation following hospital discharges to facilitate the best possible functional gains and community reintegration.

One of the important reasons that stroke survivors require continued rehabilitation on returning home is that in the Western Cape post stroke tertiary hospital admissions are short, averaging between 5 to 14 days (Cawood & Visagie, 2016; Scheffler & Mash, 2020). Although the average length of admission for rehabilitation at specialised centres is longer (28 days for brain injuries or strokes and 90 days or longer for spinal cord injuries), a very small number of stroke survivors are admitted for intensive in-patient rehabilitation at specialised centres such as the Western Cape Rehabilitation Centre (WCRC) (Cawood & Visagie, 2016). Subsequently, most stroke survivors are referred to Community Healthcare Centres (CHCs) while still in the sub-acute stages of recovery, therefore necessitating rehabilitation after discharge from hospital (Rhoda & Hendry, 2006; Bryer et al., 2010).b

For example, in addition to the rehabilitation of the physical and psychological deficits that demand attention, stroke survivors need assistance to transition from the hospital back into

their homes and reintegrate into their communities (Walsh et al., 2015; Scheffler & Mash, 2020). This includes addressing aspects such as social and leisure participation and resuming previous roles in their homes and larger communities (Sander, Clark & Pappadis, 2010; Walsh et al., 2015). Community reintegration is therefore understandably a critical part of experiencing a high quality of life for stroke survivors (Kusambiza-Kiingi, Maleka & Ntsiea, 2017).

The increased survival rates and extensive nature of the rehabilitation needs of stroke survivors post discharge, has placed increasingly demands on the rehabilitative health services in the communities that facilitate community reintegration. In particular, occupational therapy that provides services that improve stroke survivors day to day function (Govender et al., 2019). This especially important in South Africa, where stroke survivors often received limited in-patient rehabilitation and are discharged home while still functionally dependent (Ntsiea, 2019).

Research suggests that limited levels of community reintegration are being achieved by stroke survivors in South Africa in general and in the Western Cape in particular (Hassan, Visagie & Mji, 2012). Although current best practice evidence supports early discharge, early discharge needs to be accompanied by continued support and rehabilitation in the community (Bryer et al., 2011; Mayo, Bernhardt & Zorowitz, 2016). This poses a challenge within the South African context because out-patient rehabilitation at the community level is often not delivered with the same intensity as in an in-patient rehabilitation unit (Bryer et al., 2011) and community- based services which particularly include the facilitation of community reintegration are limited (Govender et al., 2019).

Several reasons have been proposed for the lack of rehabilitation taking place at community level and the inadequate levels of community reintegration being achieved by stroke survivors. Reasons include the shortage of rehabilitative services in the community, poorly coordinated existing services, and unclear referral pathway guidelines (Rhoda, Mpofu & Deweerdt, 2009; Motswaledi, Phaahla & Motsoso, 2016) resulting in infrequent rehabilitation contact sessions once stroke survivors are discharged home (Rhoda, Mpofu & Deweerdt, 2009; Motswaledi, Phaahla & Motsoso, 2016). A study conducted in the Eastern Metro Health Subdistrict (Eastern SD) reported that only 50% of stroke survivors had received physiotherapy and occupational therapy as an in-or out-patient and only 20% had received more than 10 hours of physiotherapy and occupational therapy respectively (Cawood & Visagie, 2016). This is alarming, considering that, as mentioned, most stroke survivors require ongoing rehabilitation when they return home

and that out-patient occupational therapy intervention at clinic level has been shown to significantly increase functional independence gains after a stroke (Cawood & Visagie, 2016).

Additionally, while working in the Eastern SD as an occupational therapist from 2016-2018 the researcher experienced similar challenges and found that community occupational therapists focused more on acute rehabilitation for stroke survivors to regain function in their Activities of Daily Living (ADL), often leaving limited to no time to facilitate community reintegration through home-visits, advocacy, health promotion and support groups.

Although some studies have explored the functional outcomes of stroke survivors in the Western Cape (Hassan, Visagie & Mji, 2012; Cawood & Visagie, 2016; Gretschel, Visagie & Inglis, 2017) and several other studies have explored the barriers and facilitators to community reintegration in the Western Cape (Cawood & Visagie, 2015; Walsh et al., 2015) no study could be found that explored these facilitators and barriers from the perspective and experience of stroke survivors as well as occupational therapists servicing the same area. Understanding if the perceived barriers and facilitators to community reintegration are the same between stroke survivors and occupational therapists will highlight where service delivery should be adjusted to align priorities and achieve the desired community reintegration after a stroke. This study hopes to highlight these factors and extend the body of knowledge specifically for service delivery in the Eastern SD of the Western Cape.

1.2 PROBLEM STATEMENT

Current evidence from under resourced countries propose the integration of rehabilitation services into a Primary Health Care (PHC) as an approach to facilitate community reintegration of newly disabled people (including stroke survivors) following hospital-based intervention (Govender et al., 2019). One proposed method is through applying the Community-Based Rehabilitation (CBR) philosophy, where communities are encouraged to take ownership of their health and disability needs, especially when resources are lacking (Govender et al., 2019).

As mentioned, in South Africa, hospital-based admissions tend to be short (Cawood & Visagie, 2016; Scheffler & Mash, 2020) and stroke survivors are discharged still requiring acute intervention to promote their maximal physical recovery (Rhoda & Hendry, 2006; Bryer et al., 2011). Additionally, even those stroke survivors that received an average 28 days of intensive in-patient rehabilitation at the only public rehabilitation centre in the Western Cape (Western

Cape Governement, 2006), still achieved poor levels of community reintegration (Joseph & Rhoda, 2013; Gretschel, Visagie & Inglis, 2017). It seems that despite having received intensive rehabilitation, the carry over into the home and community environment remains lacking showing some shortcomings in how rehabilitation, especially occupational therapy, is currently delivered in the community.

Several studies have explored the levels community reintegration achieved by stroke survivors in South Africa and in the Western Cape (Hassan, Visagie & Mji, 2012; Gretschel, Visagie & Inglis, 2017) as well as assessing the environmental barriers and facilitators experienced (Cawood & Visagie, 2015). However, most of these studies were quantitative in nature and provided limited insights into the perceptions and lived experiences of the stroke survivors. Only one study could be found conducted in Eastern SD that evaluated the functional outcomes of stroke survivors in this area post stroke, but the results largely focussed on the rehabilitation services received and not the participants perceptions and experiences of the barriers to occupational performance (Cawood & Visagie, 2016).

Additional studies have considered the demographic and medical profile of stroke survivors receiving therapy at community level (Rhoda & Hendry, 2003) and rehabilitative services available in the communities (Rhoda & Hendry, 2006), but again these studies were also quantitative in nature. Recently, a study was conducted to explore the perceived barriers and facilitators to integrating occupational therapy services at the PHC level (Jejelaye, Maseko & Franzsen, 2019), but this study was not specific to stroke rehabilitation. No studies could be found that explored how occupational therapists in the Eastern SD experience delivering a service that facilitates community reintegration of stroke survivors and what they considered are the perceived and experienced facilitators and barriers to providing such as service.

Priorities regarding community reintegration between occupational therapist and stroke surivors often differ (Walsh et al., 2015) and for treatment to be truly cleint-centred occupational therapist need to know what specific changes are needed to improve a service (Wilkins et al., 2001). This includes providing opportunties for service users to give feedback on the services they receive (Wilkins et al., 2001). It would therefore be valuable to determine what the percieved barriers and facilitators to community reintegration are from the perspective of stroke surivors as well as from the occupational therapists that service the same area. From the Occupational Therapist's view point it would be valuable to determine what they percieve are

the barriers or facilitators for community reintegration in terms of the stroke survivor and their envionment as well as from a service deliverly perspective.

No study could be found that provided this information for the Eastern SD and this study will contribute to the body knowledge in this regard.

1.3 RESEARCH QUESTION

This study seeks to answer the following two research questions:

- What are the experiences of stroke survivors regarding community reintegration in the Western Cape, 1 to 3 years after in-patient rehabilitation at WCRC?
- What are the perceived barriers and facilitators to community reintegration as perceived and experienced by the stroke survivors and community-based occupational therapists in the Eastern SD of the Western Cape?

1.4 AIM OF THE STUDY

The study firstly aimed to explore the lived experience of stroke survivors residing in the Eastern SD of the Western Cape, returning home, and reintegrating into their communities after having received intensive in-patient rehabilitation following their stroke. Secondly, it aimed to determine what these stroke survivors perceived and experienced as barriers or facilitators to their community reintegration. Lastly, the study intended to determine the perceived and experienced barriers and facilitators to providing community reintegration services to stroke survivors in the Eastern SD of the Western Cape, that occupational therapist encountered. This included what occupational therapists perceived and experienced as facilitators or barriers in terms of stroke survivor's personal and environmental factors as well as the context of service delivery. This in turn, would allow the researcher to make a comparison between the experiences of the service users and the service providers.

1.5 OBJECTIVES OF THE STUDY

- To explore the experienced and perceptions of stroke survivors living in the Eastern SD of the Western Cape on reintegrating into their communities using an occupational therapy lens.

- To explore the perceived barriers to community reintegration as experienced by the stroke survivors and community-based occupational therapists in the Eastern SD of the Western Cape.
- To explore the perceived facilitators to community reintegration as experienced by the stroke survivors and community-based occupational therapists in the Eastern SD of the Western Cape.

1.6 JUSTIFICATION AND USE OF THE RESULTS

Community reintegration is an internationally accepted occupational therapy outcome for stroke survivors (American Occupational Therapy Association, 2020). In the context of occupational therapy service provision at community level Western Cape, even when patients have received intensive in-patient therapy rehabilitation, treatment focused directly on the community reintegration of stroke survivors is limited (Hassan, Visagie & Mji, 2012; Joseph & Rhoda, 2013). Understanding the lived experiences of community reintegration, as well as the perceived barriers and facilitators experienced by service users and service providers will provide valuable information that can be used in the following ways:

Firstly, understanding the experiences and barriers that stroke survivors face during their community reintegration post stroke, will enable the redesign of contextually relevant, person-centred, and outcome-based programmes. Secondly, this information could help identify whether stroke survivors receive adequate rehabilitation to enable successful reintegration into their communities during admission and following discharge. This could also assist in identifying health management and maintenance strategies for stroke survivors following discharge from WCRC. Lastly, policy makers and service providers could use this information to structure services that address the identified barriers and capitalise on the facilitators to strengthen service delivery (Stark, 2001; Daly et al., 2007).

1.7 ORGANISATION OF THE RESEARCH REPORT

This research report is organised into six chapters as set out in Figure 1.1.

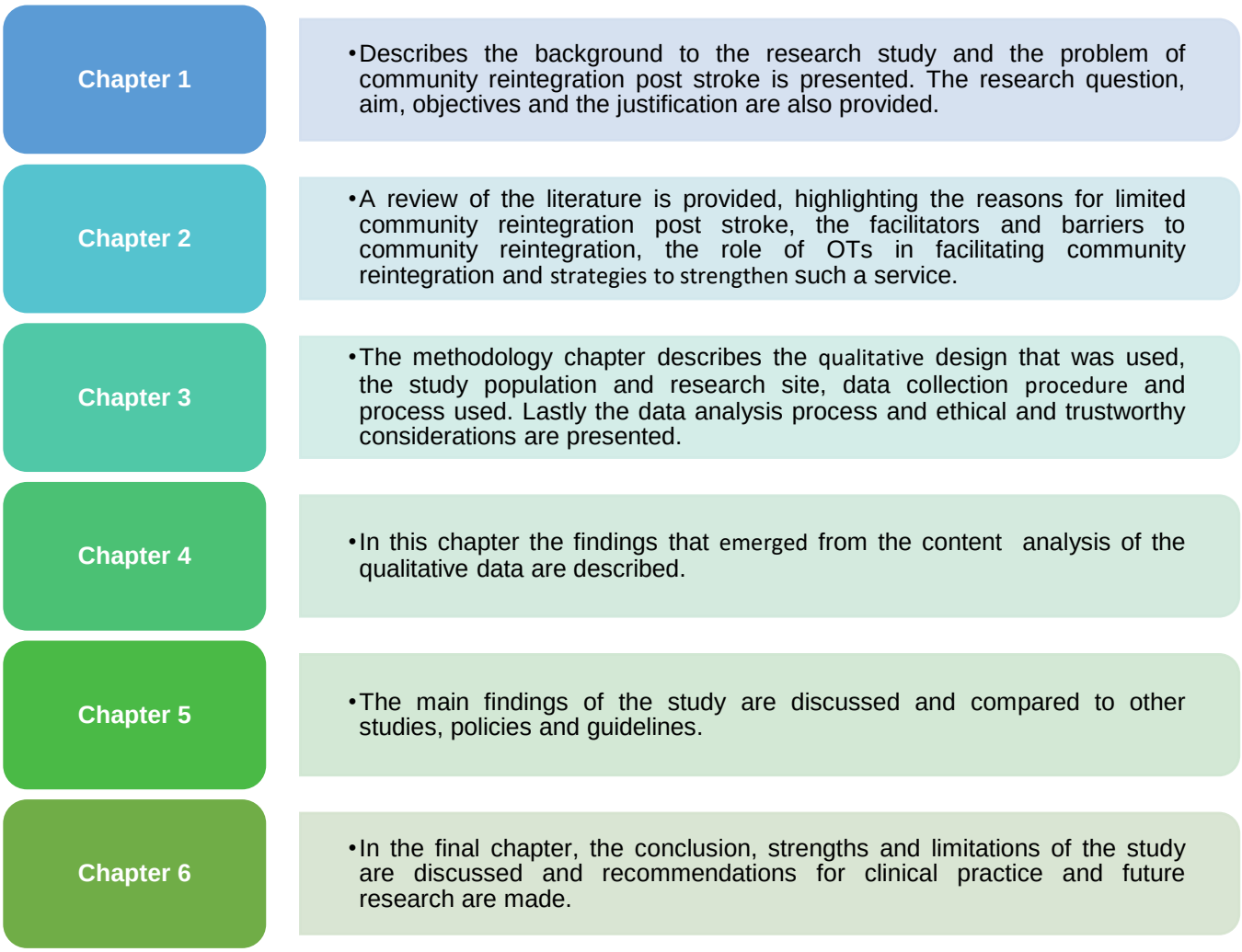


Figure 1.1 Organisation of the research report

CHAPTER 2: THE LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 INTRODUCTION

The end goal of rehabilitation for stroke survivors who have suffered a life changing incident is that they can return home and become active participants in their homes and communities within the limitations of any residual disability (Motswaledi, Phaahla & Motsoso, 2016). Occupational therapists have a key role to play in facilitating the community re-integration process due to the holistic, person-centred and occupation driven base of the profession and its view on health and wellness (World Health Organisation, 2007; American Occupational Therapy Association, 2020). Often this role needs to take place at community level, for while stroke survivors, even those with mild to moderate strokes, receive in-patient intervention in the acute phase (Bryer et al., 2011), community-based services are required to ensure reintegration is successful for both the stroke survivor and his/her family (Walsh et al., 2015). Additionally, services situated in the community are more cost-effective and ultimately reduce the demands on the health system (SA Department of Health, 2020a).

This chapter aims to highlight the existing knowledge on the reintegration of stroke survivors into their communities and the community services needed to achieve this, including existing knowledge of the barriers and facilitators to this process. The South African context will be emphasised with the focus on the current drive towards Universal Health Coverage (UHC) and the implementation of National Health Insurance (NHI). The cost benefits of community-based services will be explored taking into consideration that non-communicable diseases, like stroke, are within the quadruple burden of disease in South Africa. Additionally, areas will be highlighted where further research is required, henceforth guiding the research study.

The literature was searched through the World Wide Web using various databases such as EBSCO, PubMed and CISCO that were accessed through the University of Witwatersrand's e-library. Terms that were used to search for literature were: stroke, community reintegration, community occupational therapy, rehabilitation, facilitators, and barriers. Literature was searched from various sources including occupational therapy, physiotherapy, nursing, disability, humanities and social sciences, medical and neurosurgery journals. Several international and South African guidelines, policies, and legislation were also used. The

literature search focussed on studies in the Western Cape, South Africa, Sub-Sahara Africa and America, Canada, and Australia between the period of 2010-2021 although some older relevant studies were also included.

2.2 PREVALENCE AND COSTS OF STROKE IN SOUTH AFRICA

Stroke is currently high on the research agenda within the health sector worldwide and in South Africa for several reasons: the high prevalence and mortality rates (StatsSA, 2016); stroke is the seventh leading cause of disability adjusted life years (Mukherjee & Patil, 2011); and ranks as the ninth most significant reason for disability (Bryer et al., 2010; Bertram et al., 2013; Maredza, Bertram & Tollman, 2015). Subsequently, the financial burden of stroke in South Africa is high (Maredza & Chola, 2016).

Costs ascribed to stroke management are divided into direct cost and indirect cost. Direct cost include the cost of diagnosing, in-patient care (including the hospital bed, health professional services, surgical intervention and tests), out-patient care (including diagnostic visits and chronic medication) and the cost of prevention programmes (Maredza & Chola, 2016). In South Africa, during the period of 2014 to 2018 the total direct cost of stroke was R7.3 trillion with an average expenditure of R205,282.6 per patient (Maredza & Chola, 2016).

Additional to these costs are the indirect costs which include financial losses due to family members taking off from work to be caregivers, sick days taken and the inability to return to work (Maredza & Chola, 2016). One indicator of indirect cost are the disability grant pay outs made to stroke survivors due to the low return to work rates (Louw et al., 2020). For example, over a period of 5 years, South Africa spent a cumulative amount of R159 million on disability pay-outs for stroke survivors only (Louw et al., 2020).

Considering that South Africa's GDP loss due to diabetes, stroke and coronary heart disease was estimated at R26 billion, the urgency to develop efficient prevention and management strategies is clear (SA Department of Health, 2020a).

2.3 SERVICE DELIVERY STRATEGIES FOR STROKE REHABILITATION WITHIN THE SOUTH AFRICAN CONTEXT

Cost effective management include investing into the prevention and control of non-communicable diseases like stroke (SA Department of Health, 2020a). A starting point is integrating current policies, strategies and programmes across all levels of care with a specific

focus on the primary levels of healthcare (SA Department of Health, 2020a). Over the years, several legislative and regulatory policies have been developed that contribute to the prevention and management of strokes in South Africa. For instance, the Tobacco Products Control Act No 83 of 1993, the Regulation on Trans-fats in Foodstuff in 2011, the regulation in the reduction of sodium in 2013, the regulation regarding warning labels on alcohol products in 2017 and the Draft control of Tobacco Products and Electronic Delivery Systems Bill of 2018 are legislations that implemented preventive measures (SA Department of Health, 2020a).

Additional to legislation, several frameworks and strategies have been developed to manage strokes by addressing access to health care and provision of rehabilitation services.

2.3.1 The Constitution of the Republic of South Africa

The Constitution of the Republic of South Africa (*The Constitution of the Republic of South Africa, Act 108 of 1996*, 1996) declares that everyone has the right to accessible health care services, social security and appropriate social assistance if they are unable to support themselves or their dependents. This is often the case post stroke (Maleka, 2010; Rhoda et al., 2015). Furthermore, it is the state's responsibility to take reasonable measures to ensure these rights (*The Constitution of the Republic of South Africa, Act 108 of 1996*, 1996).

2.3.2 Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015- 2020

South Africa signed the United Nations (UN) Convention on the Rights of persons with disabilities which also concurs with the obligations of the state as specified in the Constitution described above (Motswaledi, Phaahla & Motsoso, 2016). Guided by this policy framework and in addition to other national acts, the Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020 (FSDR) was developed in 2015. This strategic document aimed to guide the advancement of rehabilitation service delivery in South Africa for various health conditions and disabilities. The FSDR emphasises comprehensive rehabilitation services including promotion, prevention, curative treatment, rehabilitation and palliative care (Motswaledi, Phaahla & Motsoso, 2016). The vision of the FSDR was to integrate rehabilitation services at PHC level so that appropriate, accessible, and affordable services are provided to Persons with Disabilities (PwD) throughout their life course, including stroke survivors. The FSDR claims to be based on the philosophy of CBR by encouraging intersectoral collaboration in the five core components of the CBR matrix, namely, health, education, livelihoods, social

life, and empowerment (Motswaledi, Phaahla & Motsoso, 2016). Nonetheless, the FSDR still follows a top-down medical model of service delivery by providing strategies to deliver rehabilitation services to the community but neglecting to include how the community and PwD can take ownership of their own health.

Striving to providing a guideline for the integration of rehabilitation services at PHC level, the FSDR (2016) defined seven levels of care where rehabilitation should take place, namely homes, schools, PHC facilities, regional hospitals, tertiary hospitals, centralised hospitals, and specialised hospitals.

In general, hospital-based services should provide specialised services focussed on assessing, managing, and treating patients with stroke within a multidisciplinary team (MDT) while referring patient up to more specialised centres or down to PHC level. Tertiary hospital services should be more focussed on ICU and theatre and centralised hospitals are recommended to refer issuing of devices to lower levels due to the short admission period. Stroke survivors receiving treatment in regional, tertiary, or centralised hospitals should be in the acute or the initial few days of sub-acute recovery. When patients have achieved physiological stability, they can be managed in specialised hospitals or rehabilitation centres such as WCRC until they have sufficient ability to reintegrate into their home (Western Cape Governement, 2017). Specialised hospital should provide rehabilitation services to stroke survivors that have severely disabling conditions during their sub-acute phase of recovery. The aim is to provide intensive rehabilitation that will improve functional skills and allow patients to reintegrate into their communities (Motswaledi, Phaahla & Motsoso, 2016). Community reintegration should then be facilitated through community-based services and support groups (Landrum, Schmidt & McLean, 1995).

The FSDR proposed that PHC rehabilitation should include screening, assessment, and treatment (Motswaledi, Phaahla & Motsoso, 2016). This would include conducting home visits, health promotion actions, training of community health workers and providing rehabilitation services at other non-health facilities. At PHC level it was proposed that only minor assistive devices and wheelchair repair should be provided. Lastly, rehabilitation should also take place in stroke survivors' homes. Here, a rehabilitation therapist should provide specific intervention in clients homes during home visits which should then be followed up by community workers and peer support councillors. Vocational screening and referral should also take place.

Advocacy for PwDs to be included in decision making and planning of intervention programmes should be emphasised (Motswaledi, Phaahla & Motsoso, 2016).

As shown above, physiological stability and initial strengthening should take place at hospital level, more intensive rehabilitation at a specialised centre and the facilitation of community reintegration and return to work at community level, in PHC facilities or in client's homes (Landrum, Schmidt & McLean, 1995; Motswaledi, Phaahla & Motsoso, 2016; Western Cape Governement, 2017).

It is important to note that there are only two specialised rehabilitation government facilities such as the WCRC in the country, only a small number of district hospitals have adequate rehabilitation units and these are mainly in urban areas (Motswaledi, Phaahla & Motsoso, 2016; Taylor & Ntusi, 2019). Together with inaccessible and unaffordable transport, stroke survivors consequently often have challenges in accessing services that would provide the needed intensive rehabilitation (Motswaledi, Phaahla & Motsoso, 2016). The FSDR therefore emphasises the importance of rehabilitation taking place in the community by decentralising services and indicating how services should be implemented at different levels of care (Motswaledi, Phaahla & Motsoso, 2016).

2.3.3 The Western Cape Government Health's Healthcare Strategic Framework 2020-2025 and Healthcare 2030 Policy

In the Western Cape, the department of health has committed to the ideals of the "Healthcare 2030" policy (Western Cape Government, 2014a) and based its service delivery plan on a Community Orientated Primary Care (COPC) approach for the redesigning of PHC services (Western Cape Governement, 2017; Western Cape Government, 2020).

Healthcare 2030, in line with the FSDR, proposes a rehabilitation service delivery platform that will be provided by specialised services, specialised hospitals, tertiary and central hospitals, regional hospitals, district hospitals and PHC services as depicted in Figure 2.1 (Western Cape Government, 2014a).

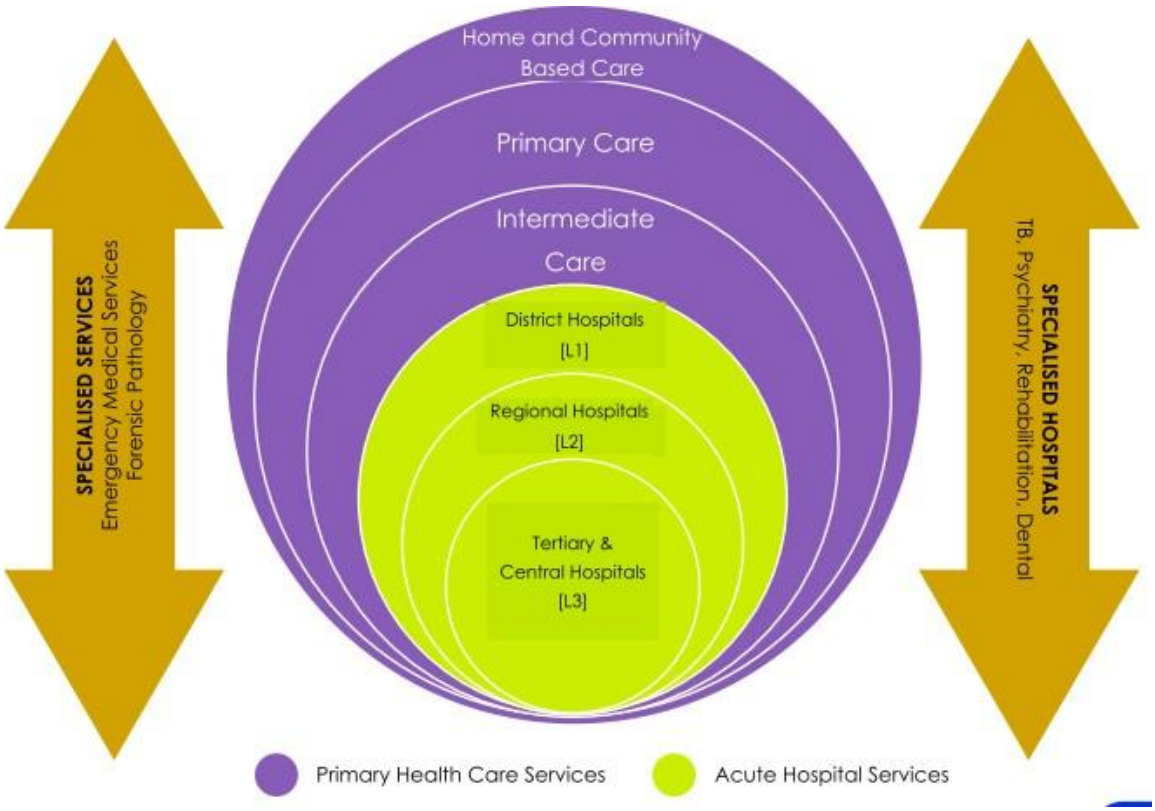


Figure 2.1 Western Cape Health Service Delivery Platform 2030

Of these service delivery platforms, the main emphasis is on the PHC services which will consist of three service deliver platforms: Home and Community-Based Care, Primary Care Services at health facilities and Intermediate Care.

Home and Community-Based Care services will focus on prevention and health promotion while also playing an assisting role in curative, rehabilitative and palliative care services. The core team will consist of a professional nurse and Community Healthcare Workers (CHWs). The service will focus on primary and secondary preventions but will also provide basic levels of rehabilitative interventions. Rehabilitation at this level must focus on activity limitations and participation restrictions and assisting patients to develop self-management strategies. According to the Healthcare 2030 Policy (Western Cape Government, 2014a) rehabilitation services at this level will be provided by Community Rehabilitation Workers (CRWs), who are midlevel workers with basic training on rehabilitative skills. The CRWs will be directed and supervised by professional therapist such a physiotherapist, occupational therapist, speech therapists and dieticians.

Primary Care Services will be provided at PHC facilities (including mobile and satellite clinics) and focus on curative and preventative care. This service is nurse driven and the core team will consist of clinical nurse practitioners supported by a medical officer. Rehabilitation services at this level focus on body structure and functional impairments which can be resolved quickly. Service delivery will also include the provision of assistive devices like mobility aids. The Healthcare 2030 policy (Western Cape Government, 2014a: 53) stipulates that "while the nurse practitioner and medical officer in primary care will have some basic knowledge and skills in rehabilitation, they will be supported by therapists and therapy assistants in a range of areas that includes physiotherapy, speech therapy, occupational therapists, audiologists and dieticians".

Intermediate care will provide in-patient care that focuses on enabling patients to regain skills and abilities within activities of daily living where the outcome is to be discharged home or to an alternate supported living environment. These services will be provided by CRW working under the direct and clinical supervision of a professional therapist but will deliver the majority of the therapy.

Unfortunately, a recent study conducted by Scheffler and Mash (2019) already identified several limitations in the practical applications of above mentioned service delivery platform. For instance, in the Cape Winelands area, there are five intermediate care facilities where each only allocates two to three beds for rehabilitative care. Subsequently providing a maximum of 12 rehabilitations beds for the whole area. District therapists are responsible for the assessment and development of treatment plans for these patients, but the therapy is then delivered by CHWs or nursing staff with no specific rehabilitation training. What's more, the "Healthcare 2030" policy stipulates that CRWs should provide services in home and community-based services as well as at intermediate care facilities, but there are no posts for this cadre of health worker available in the area (Scheffler & Mash, 2019). Furthermore, those who are working, sometimes provide services without regulation and adverse patient outcomes have been reported due to uncoordinated care (van de Ruit, 2019).

2.3.4 The National Health Insurance Bill and Universal Health Care

The concept of UHC was introduced by the UN based on the principle that health is a precondition for all and access to health care should not incur financial hardship (Western Cape Government, 2020). Based on the goals to achieve UHC, the South African government

proposed two means of achieving UHC, through the NHI fund and though PHC reengineering (Michel et al., 2020).

In 2011, the South African health minister introduced the NHI Green Paper, which seeks to provide all South Africans with UHC through the establishment of a NHI fund (SA Department of Health, 2017; Michel et al., 2020). The aim is that the NHI fund will integrate private and public health care by pooling resources into a single fund that covers all South African citizens, irrespective of their income, and therefore enabling access to health care services by all as well as improving the quality of care (Michel et al., 2020).

In 2019 the UN General Assembly committed to achieving UHC by 2030 and challenged member countries to redesign PHC services to support wellness, provide comprehensive care for people with chronic diseases, improve access to care and increase the productivity of services by ensuring an adept workforce to manage the services (Western Cape Government, 2020). As part of this PHC reengineering process, the NHI Bill (2017) proposes PHC to be the first point of contact when accessing the healthcare system (SA Department of Health, 2017). Community orientated health services should aim to meet most of the health care needs of the population in a specific catchment area. Should users then need more specialised services they will be referred as required. The delivery of PHC services will be based on the Ideal Clinic Model which includes access to a MDT, including rehabilitation services (SA Department of Health, 2017, 2018).

Lastly, one proposed way to address the current shortage of health care staff in the public sector will be to contract private health care practitioners including occupational therapists into the PHC facilities (SA Department of Health, 2017).

2.4 BEST PRACTICE FOR STROKE REINTEGRATION USING THE COMMUNITY BASED REHABILITATION PHILOSOPHY

2.4.1 Evidence for Early Supported Discharge and home-based rehabilitation

In line with the CBR philosophy, current international literature supports the concept of stroke rehabilitation taking place at community level and in the home to best facilitate community reintegration (Mayo, Bernhardt & Zorowitz, 2016; Adeoye et al., 2019; Neale et al., 2020). Over the past decade there been a change in focus from hospital-based rehabilitation to Early Supported Discharge (ESD), with stroke clinical guidelines worldwide recommending ESD for

stroke survivors with mild to moderate impairments (The European Stroke Organisations (ESO) & ESO Writing Committee, 2008; National Institute for Health and Care Excellence, 2013; Hebert et al., 2016; Intercollegiate Stroke Working Party, 2016; Stroke Foundation, 2017; Adeoye et al., 2019). ESD entails a shorter hospital admission followed by referring stroke survivors to PHC level facilities for continue rehabilitation with the support of a rehabilitation team and other services in the community (National Institute for Health and Care Excellence, 2013; Langhorne, Baylan & Trialists, 2017).

Early Supported Discharge of stroke survivors has been found to result in a shorter initial hospital stays (3 to 8 days less) (Langhorne, Baylan & Trialists, 2017; Neale et al., 2020), decreased morbidity, reduced dependence with increased participation in ADLs and a lower prevalence of hospital readmissions in developing and developed countries (Langhorne, Baylan & Trialists, 2017). A study conducted in Australia found that owing to the short hospital admissions, ESD is more cost-effective (Neale et al., 2020). Additionally, many stroke survivors have trouble moving from a rehabilitation setting back to their communities, resulting in loneliness, low moods and a poor quality of life (QoL) (Mayo et al., 2002; Wood, Connelly & Maly, 2010), emphasising the need to supported discharge.

Consistent with international guidelines the South African Guideline for Stroke Management (Bryer et al., 2011) advocates for earlier discharge of stroke survivors who are medically stable, have a mild to moderate impairment and can receive rehabilitation in the community from a MDT that has experience with strokes. At the same time not all stroke survivors are eligible for ESD due to being too ill for early discharge or not having the appropriate support at home (Mayo, Bernhardt & Zorowitz, 2016). It has been reported that stroke survivors discharged without the needed community support have a higher risk of mortality (Bryer et al., 2011)(Bryer et al., 2010). The South African Guideline for Stroke Management (2010) also emphasises that rehabilitation should continue for a year after being discharged from hospital. Moreover, structures should be put in place that will improve home-base care and training. Proposed structures include firstly the education of caregivers and patients regarding stroke and cardiovascular risk factors. Secondly, regular monitoring of stroke survivors blood pressure, treatment and compliance by nurses and home-based carers after discharged from the hospital. Thirdly, the in-service training of health care professional regarding the protocols of managing acute strokes so that the outcomes can be improved after discharge to the community. Lastly,

in the absence of sufficient therapist to provide rehabilitation services, the training of caregivers so that they can play a more active role (Bryer et al., 2011).

2.4.2 Evidence regarding the importance of community reintegration

The FSDR highlights that rehabilitation should assist clients to regain as much functional abilities with the end goal of going home and reintegrating into their communities (Motswaledi, Phaahla & Motsoso, 2016). Similarly the CBR philosophy emphasises that rehabilitation should aim to include and reintegrate people with disabilities into all aspects of community life (Sherry, 2014).

Community reintegration refers to a person's ability to engage in a broad spectrum of activities that include the roles they play in their household, their role in the family as well as the ability to engage in productive activity, leisure, social interaction and interactions in the broader community (Sander, Clark & Pappadis, 2010). The inability to engage in these tasks have been reported to negatively impact stroke survivors' experience of QoL (Kusambiza-Kiingi, Maleka & Ntsiea, 2017). Three main factors have been identified that influence the QoL that stroke survivors experience and can be directly influenced through the process of community reintegration.

2.4.2.1 The need to engage in meaningful activities

Several international and South African studies have found that the lack of engagement in meaningful activities leads to decreased satisfaction and QoL experienced by stroke survivors (Moeller & Carpenter, 2013; Gretschel, Visagie & Inglis, 2017; Kusambiza-Kiingi, Maleka & Ntsiea, 2017). The physical limitations after a stroke often challenge participate in self-defining and productive activities such as education, volunteer work and employment (Moeller & Carpenter, 2013; Rhoda et al., 2015; Turner et al., 2019). This in turn is reported to result in negative feeling such as frustration, poor self-esteem, depression, a loss of identity and feeling a lack of contribution to society (Wood, Connelly & Maly, 2010; Moeller & Carpenter, 2013; Trani et al., 2020). Likewise, restricted participation in family commitments due to fatigue have also been found to directly impact stroke survivors' confidence and mood (Turner et al., 2019).

2.4.2.2 The need for social interaction

Although independent participation in activities of daily living has been associated with Health-Related QoL (Algurén et al., 2012; Chou, 2015; Kariyawasam, Pathirana & Hewage, 2020),

several international and African studies have found that social participation has a strong correlation with a high QoL for stroke survivors (Moeller & Carpenter, 2013; Chou, 2015; Bello et al., 2020).

Several secondary effects of strokes, such as cognitive impairments and speech deficits, directly influence social interaction (Moeller & Carpenter, 2013). Cognitive deficits, such as memory loss, have been reported to cause a decreased sense of time and context resulting in feelings of detachment (Moeller & Carpenter, 2013). Often these deficits can be subtle but have been reported as making it difficult to follow instructions, maintain concentration and follow group conversations (Turner et al., 2019). Speech related cognitive deficits also have been reported to cause frustration and directly impact stroke survivors' confidence and can lead to social isolation (Turner et al., 2019). The social isolation often experienced after a stroke has been found to leave stroke survivors feeling frustrated, dissatisfied, angry and depressed (Dowswell et al., 2000; Cunningham & Rhoda, 2014).

Moreover, mobility limitations such as the inability to drive has also been reported to cause a decreased sense of autonomy and independence (Moeller & Carpenter, 2013; Bello et al., 2020) which influence a stroke survivors' ability to leave the home and participate in social events (Rhoda et al., 2015; Tashiro et al., 2019).

2.4.2.3 The need for acceptance and inclusion in the broader community

In South Africa, the need for stroke survivors to belong and contribute to others is especially important because of the philosophy of ubuntu that is found in many communities (Mabovula, 2011; Mji, 2013). Many individual's cultural perspectives are founded in this philosophy, where the individuals is viewed within the context of their relationships with others (Mabovula, 2011). A study conducted amongst older Xhosa women in the Eastern Cape found that being healthy included the ability to participate in important activities such as being able to rear children and produce food for the village (Mji, 2013; Ned, Cloete & Mji, 2017). Therefore, a stroke survivor may be viewed as inferior by the community due to not being able to contribute to their household (Wegner & Rhoda, 2015; Rohwerder, 2018) with resultant stigmatisation (Rohwerder, 2018). This in turn places them at a high-risk of developing depression and a low self-esteem (Trani et al., 2020).

To conclude, it is important to note that a prominent challenge for stroke survivors is not necessarily the lack of independence experienced, but the social isolation and loss of meaning that accompanies it (Moeller & Carpenter, 2013). In contrast, many occupational therapists focus on achieving independence in self-care, leisure and productivity tasks but do not consider the important contribution to wellbeing that is found through being able to contribute to other's wellbeing (Hammell & Iwama, 2012). By shifting the focus of treatment from a medical model to an more occupation-based model and encouraging self-management, as found in the CBR philosophy, the International Classification of Function (ICF) and other social models, stroke survivors can be offered the opportunity to achieve increased independence in areas that they perceive as important to wellbeing and QoL (Jejelaye, Maseko & Franzsen, 2019).

2.5 REALITIES OF CURRENT SERVICE DELIVERY AT PHC LEVEL IN SOUTH AFRICA

Unfortunately, despite clear guidelines regarding the importance of rehabilitation taking place at community level, ESD and facilitating community reintegration for stroke survivors in South Africa, the reported levels of community reintegration remains low (Joseph & Rhoda, 2013).

2.5.1 Lack of community reintegration being achieved by stroke survivors

In the Western Cape, rehabilitation outcomes are classified according to five rehabilitation outcome levels (Western Cape Governement, 2006). These outcome levels are based on Landrum, Schmidt and McLean's (1995) clinical outcomes for rehabilitation which include physiological instability, physiological stability, physiological maintenance, residential reintegration, community reintegration and productive activity. Not only do the outcome levels outline a patient's clinical level of recovery but they also determine the intervention that should take place during the different stages of rehabilitation (as outline in Appendix A).

One can argue that the stroke patients were maybe discharged too early, but Hassan, Visagie and Mji (2012) found that, despite stroke survivors having progressed to a level where they are ready for residential reintegration on discharge, on follow-up the picture was less positive. The study found that only 37% of stroke survivors showed improvement in one or two outcome levels after discharge home, while only 9% achieved the productive activity outcome level (Hassan, Visagie & Mji, 2012).

These findings in the Western Cape concur with reports of poor community reintegration found in other provinces such as Gauteng and the Eastern Cape (Cunningham & Rhoda, 2014; Kusambiza-Kiingi, Maleka & Ntsiea, 2017). This raises the question as to why stroke survivors are not reintegrating effectively into their communities. Studies across South Africa have proposed the following reasons which are highlighted in section 5.2.

2.5.2 Service and resource related reasons for the limited community rehabilitation of stroke survivors in South Africa

In South Africa, one of the main contributing factors to limited community reintegration is the poor continuity of rehabilitation of stroke survivors after being discharged home, especially services provided by skilled therapist that facilitate community reintegration (Rhoda, Mpofu & Deweerdt, 2009; Hassan, Visagie & Mji, 2012). In spite of the short average length of stay in hospital for stroke survivors in South Africa (Cawood & Visagie, 2016; Scheffler & Mash, 2020), the support after discharge is often lacking with resultant poor community reintegration. (Hassan, Visagie & Mji, 2012; Joseph & Rhoda, 2013; Gretschel, Visagie & Inglis, 2017; Kusambiza-Kiingi, Maleka & Ntsiea, 2017). Joseph and Rhoda (2013) found that only 20% of their participants received medical or rehabilitation services in the community after being discharge from an in-patient rehabilitation centre in the Western Cape. Similarly, Scheffler and Mash (2020) found that stroke survivors in rural Western Cape had an average hospital stay of 5 days and most were discharged home without any training given to their caregivers. Rehabilitation services in the area were reported to be limited and stroke survivors were often referred to the care of CHW, where intervention focused on basic nursing and health promotion instead of rehabilitation aimed at achieving functional goals (Scheffler & Mash, 2019, 2020).

The literature has highlighted several reasons for the lack of continued rehabilitation to promote community integration which are explored below.

2.5.2.1 Poor implementation of the referral pathways guidelines

Poor implementation of guidelines, such as the “Referral Policy for South African Health Services and Referral Implementation Guidelines” (SA Department of Health, 2020b) and “The South African guideline for the management of ischemic stroke and transient ischemic attack” (Bryer et al., 2011), has a direct impact on the continuation of therapy and the levels of community reintegration achieved by stroke survivors in South Africa (Cawood & Visagie, 2016; Scheffler & Mash, 2019). To demonstrate, a study in the Cape Winelands district of the Western

Cape, found that most stroke survivors were admitted to a hospital for a median of 5 days and only 38.5% were referred for further medical or in-patient rehabilitation (Scheffler & Mash, 2019). Furthermore, treating doctors usually determined the discharge destination, neglecting an MDT approach (Scheffler and Mash, 2019). Further studies have reported that stroke participants are often being referred to Community Health Clinics (CHCs) while in the acute stage of their condition (Rhoda, Mpofu & De Weerdt, 2011; Scheffler & Mash, 2019) requiring intensive rehabilitation (Bryer et al., 2011).

Additional to the poor implementation, currently South African stroke management guidelines and the referral pathways proposed by the Department of Health are vague regarding the exact referral procedures for rehabilitation. To demonstrated, the “Referral Policy for South African Health Services and Referral Implementation Guidelines” (SA Department of Health, 2020b) mentions that patients can referred up or down for rehabilitation but provides no specific guidelines or indication of the service providers to whom referrals should be made. The Ideal Clinic Guideline (SA Department of Health, 2018) that directs service deliver at community level only mentions the need of occupation therapy and physiotherapy service providers with no reference to specific referrals. Moreover, referral form templates such as those used by ward outreach teams do not provide rehabilitation services as an option (SA Department of Health, 2018) .Lastly, the South African guideline for the management of ischemic stroke and transient ischemic attack (Bryer et al., 2011) recommends that stroke rehabilitation should continue for the first year after discharge but does not detail the service providers. To demonstrate, the guideline indicates the need for physiotherapy at level one hospitals and that a full MDT should be available at tertiary level hospitals. No mention is made of occupational therapy at community level (Bryer et al., 2011).

2.5.2.2 Inadequate discharge planning

In addition to not being referred for continued rehabilitation, stroke survivors often do not receive comprehensive discharge planning, leaving stroke survivors feeling inadequately prepared to manage their condition and recovery on return home (Forster et al., 2012; Andrew et al., 2018; Govender et al., 2019; Scheffler & Mash, 2020).

Studies in South Africa have found that discharge preparation often consists of providing family members with quick basic education and training on the day of discharge (Rhoda & Hendry, 2003) or no caregiver training at all (Scheffler & Mash, 2019, 2020). Some patients are provided

with a referral letter for continued therapy at the nearest clinic (Rhoda & Hendry, 2003) but others receive no referral (Govender et al., 2019). The manner in which stroke survivors are discharged home from acute or rehabilitation centres has notable implications for the community reintegration and QoL experienced. Andrew *et al.* (2018) reported poor discharge preparations results in a higher prevalence of pain, anxiety, and depression within six months after discharge in stroke survivors.

2.5.2.3 A shortage of human resources, especially occupational therapists, with resultant short and infrequent contact sessions

Occupational therapists have an important role to play in facilitating community reintegration at PHC level due to their specialised skills in understanding the interaction between occupational performance, the environment and a person's health to address activity limitations (Canadian Association of Occupational Therapists, 2013; OTASA, 2015). Occupational therapists are able assist patients to find the optimal fit between these three factors and overcome the challenges they face (OTASA, 2015). This has been confirmed through several studies.

In a data meta-analysis of randomized controlled trials of occupational therapy for stroke survivors in the community, Walker *et al.* (2004) found that stroke survivor receiving community-based occupational therapy have shown significant improvement in ADLs, Instrumental Activities of Daily Living (IADLs), leisure and social participation. Hassan, Visagie and Mji (2012) further highlighted that while engaging caregivers and participating in social and religious activities can increase stroke survivors' community reintegration, other aspects, such as returning to work, need to be facilitated through the specialised skills of an occupational therapist. Accordingly, the CBR approach affirms that occupational therapy should form an integral part of PHC services (Jejelaye, Maseko & Franzsen, 2019) and community based occupational therapists are expected to provide a service that includes early identification, prevention, promotion and education in the community (Naidoo, Van Wyk & Joubert, 2017; Ned, Cloete & Mji, 2017).

Unfortunately, occupational therapy human resources in the public sector South Africa are stretched thin, especially at PHC level (Jejelaye, Maseko & Franzsen, 2019). Most occupational therapists are employed by the private sector, leaving only 25.2% employed within the public health sector which provides services for 84% of the South Africa population (Ned et al., 2020). Statistics available for 2019 estimated there are 1279 occupational therapist employed in the

public sector with a 2.64 per 100 000 public sector population density (Tiwari, Ned & Chikte, 2020). In the Western Cape the 2011 survey reported an occupational therapist ratio of 1.98 per 100,00 people but more recent statistics are not available to compare to the 2019 national ratio (SA Department of Health, 2011). The human resources are further constrained by poor staff retention (77.6% between 2002 and 2010) and a loss of occupational therapy graduates from the public health sector following completion of the compulsory community service year due to the lack of posts (SA Department of Health, 2011; Tiwari, Ned & Chikte, 2020) as well as the migration to private practices or overseas job opportunities (Sherry, 2014). Despite the limited number of occupational therapy posts, there is a high vacancy rate, especially at PHC level (Motswaledi, Phaahla & Motsoso, 2016; Jejelaye, Maseko & Franzsen, 2019), further aggravating the staff shortages. In 2010, 108 occupational therapy vacancies in the public sector were recorded in the Western Cape (SA Department of Health, 2011).

This shortage of occupational therapists as well as other rehabilitation staff in the public sector result in short and infrequent rehabilitative contact session (Western Cape Government, 2011; Ned et al., 2020), directly impacting on the levels of community reintegration that can be facilitated for stroke survivors. Often occupational therapists are also expected to render rehabilitation services in a district hospital as well as the surrounding CHC clinics (Naidoo, Van Wyk & Joubert, 2016; Visagie & Swartz, 2016; Scheffler & Mash, 2019). Crucial therapy time is often lost due to travel time (Visagie & Swartz, 2016) and therapy sessions have been found to be short and infrequent (Cawood & Visagie, 2016).

2.5.2.3 Inadequate implementation of midlevel healthcare workers

To address the shortage of staff at PHC level there was an initiative in South Africa to train midlevel rehabilitation workers known as CRWs (Binken, Miller & Concha, 2009) but also referred to as Rehabilitation Care Workers (Western Cape Government, 2014a; Ennion & Rhoda, 2016; Ned et al., 2020) or Community-Based Rehabilitation Workers (Visagie & Swartz, 2016). The CRWs were trained in the province of Limpopo, in basic rehabilitation skills that included aspects of occupational therapy, physiotherapy, speech therapy and community development and the aim was that the CRWs would provide basic supervised rehabilitation, in communities that had limited access to this service (Binken, Miller & Concha, 2009). However, this training programme was stopped by the Department of Health in 2004 and training shifted to that of discipline specific assistants (Binken, Miller & Concha, 2009). Other midlevel workers

found at PHC level are the CHWs, who have no rehabilitation skills and are mostly managed by nursing staff (Naledi, Barron & Schneider, 2011). Despite their lack of rehabilitative skills, many stroke survivors are referred to home- and community based-care which is often delivered by CHWs (Scheffler & Mash, 2019).

The current use of CHWs for rehabilitative services poses serious problems to service delivery as highlighted by a recent study conducted by Scheffler and Mash (2019). Firstly, despite the well-defined role of CHWs in terms of PHC, their role remains unclear in terms of rehabilitation. Many CHWs engage in promoting heath and assisting with basic nursing activities but do not actually engage in facilitating the functional independence of patients. Secondly, the service provision of CHWs has been found to be sporadic and inconsistent. For example, it was found that patients waited for up to 49 days before receiving their first home and community-based care visit and 30% of patients referred never received CHW visits. On the other hand, those that did receive CBC were often limited to a total of three, 20 minutes sessions (Scheffler & Mash, 2019).

The need to improve community and home base services for service provision to reach a larger proportion of the population remains challenged by the limited number of occupational therapists working at PHC level (Binken, Miller & Concha, 2009; Bryer et al., 2011). Task shifting to CHWs has been recommended as a way of improving accessibility (World Health Organisation, 2008; Naidoo, Van Wyk & Joubert, 2016). However, currently CHW's do not have the skills and knowledge to provide such as services (Scheffler & Mash, 2019, 2020).

2.5.2.4 Poor insight into the role of occupational therapy in facilitating community reintegration and limitations in support received

In addition to the shortage of occupational therapists to render community reintegration services the crucial role they should play is often misunderstood not only by other MDT members (Naidoo, Van Wyk & Joubert, 2016), but occupational therapists themselves, who are often unaware of the specific contribution they must play at community level. In addition to understanding the barriers and facilitators that the broader community poses, occupational therapist need to tailor their services to the stroke survivors' specific needs and situation. Literature highlights that occupational therapist do not consistently apply person-centred practice (Hammell, 2013) and often the priorities for community reintegration differs between that of stroke survivors and their therapists (Wood, Connelly & Maly, 2010; Walsh et al., 2015).

Some research has suggested that PwDs have expressed the need for occupational therapists to provide appropriate assistive devices, teach realistic alternative methods to completing ADL tasks and train carers in the specific tasks that they find challenging (Naidoo, Van Wyk & Joubert, 2017).

Naidoo, Van Wyk and Joubert (2016) explored the perception of occupational therapists' role at PHC level from the view point of Department of Health (DoH) managers, CHWs, PHC nurses as well as novice and experienced occupational therapists in Kwazulu-Natal, South Africa. The DoH managers, CHWs and PHC nurses had similar views acknowledging the importance of occupational therapy in health promotion, skills training, support groups and secondary prevention with the specific focus on community reintegration. Occupational therapists on the other hand described their intervention as mainly individual-based, aligned with rehabilitation policies, following a strong medical model and only partially focused on community reintegration (Naidoo, Van Wyk & Joubert, 2016). Jejelaye, Maseko and Franzen (2019) further confirmed that at community level occupational therapy services provided are mainly CHC or clinic-based services, while other services like outreach to neighbouring communities and home visits are limited.

Lastly, inappropriate supervision of occupational therapists by non-rehabilitation professionals hinders the implementation of appropriate programmes and places unrealistic or inappropriate expectations on occupational therapy service delivery (Naidoo, Van Wyk & Joubert, 2017; Ned, Cloete & Mji, 2017) as these supervisors have limited insight into the needs, roles and requirements of rehabilitation (Ned, Cloete & Mji, 2017).

2.5.2.5 Physical resource limitations

Occupational therapists have reported that limited or inappropriate treatment space and insufficient appropriate assistive devices make it challenging to provide services that would facilitate community reintegration for stroke survivors (Wegner & Rhoda, 2015; Jejelaye, Maseko & Franzsen, 2019). Additional factors such as unavailable clinic transport or inappropriate vehicles make it challenging to conduct home visits (Ennion & Rhoda, 2016; Ned, Cloete & Mji, 2017) and a lack of computers, telephones and internet make it challenging to complete administrative tasks. In addition, medical services are often prioritised above rehabilitation services, influencing budget allocations which limit the procurement of much

needed assistive devices that could be used to facilitate activity participation (Ned, Cloete & Mji, 2017).

While the deficiencies in the health care system are clear, it is important to consider that a number of other factors also play a role in the levels or community reintegrating that stroke survivors achieve as described below.

2.5.3 Additional factors influencing community reintegration of stroke survivors in South Africa

In addition to the health care related challenges, there are additional factors that play a role in how stroke survivors reintegrated into their community. The Person-Environment-Occupation-Performance (PEOP) model, developed by Christiansen, Baum and Bass (2015), considers how a person's occupational performance is influenced by the person's personal characteristics, the environment he finds himself in and the actual occupation or activity that needs to be engaged in. Using the PEOP lens, several personal factors and environmental factors were found in literature, that influence how stroke survivors reintegrate into their communities which are presented below.

2.5.3.1 Personal factors

The nature and extent of physiological, neurophysiological and cognitive effects following a stroke have a direct impact on community reintegration on a stroke survivor by decreasing interest in social activities, as well as causing dissatisfaction with the ability to participate in activities like work, recreational pursuits and travel (Edwards et al., 2006; Walsh et al., 2015). For example, stroke survivors with severe initial impairments are reported to show poor levels of recovery (Prabhakaran et al., 2008) while stroke survivors with less severe physical and cognitive impairments have been found to have a higher probability of returning to work (Hassan, Visagie & Mji, 2012).

Physiological and neurophysiological effects include decreased mobility, limited hand function, fatigue and speech deficits (Edwards et al., 2006; Cawood & Visagie, 2015; Walsh et al., 2015). Even with limited motor impairments, lasting fatigue greatly influences poststroke life (Turner et al., 2019). Cognitive impairments that have been reported in the literature are reduced attention, poor concentration and communications deficits (Edwards et al., 2006; Walsh et al., 2015).

A qualitative meta-synthesis by Walsh *et al.* (2015) reported the severity of physiological, neurophysiological and cognitive effects that a stroke survivor has do not necessarily have a linear relationship to the level of community reintegration they achieve. For instance, someone with mild physical dysfunction may achieve low levels of community reintegration due to factors such as fatigue or dysarthria (Walsh et al., 2015). However, a difference has been found between the factors influencing life satisfaction between mild stroke survivors and those who have had moderate to severe strokes (Edwards et al., 2006). Mild stroke survivors found that the challenges experienced were mainly due to stroke-related symptoms, depression and reduced participation in significant activities (Edwards et al., 2006; Turner et al., 2019). In contrast, persons with more severe stroke reported decreased psychosocial well-being and lower Health-Related QoL (Kamel et al., 2010; Seitz & Donnan, 2015; Tsalta-Mladenov & Andonova, 2021). Thus, it is important to consider that even in the case of a mild stroke, there may still be significant factors that can influence a stroke survivor's ability to reintegrate at home and in the community.

Psychological factors also play a role in the level of community reintegration achieved post stroke by stroke survivors. This is because each human being is unique and experiences a stroke in their own way (Brauer, Schmidt & Pearson, 2001). Walsh *et. al.* (2015) highlighted perseverance as the predominant personal factor that facilitates community reintegration. Additional personality traits such as the ability to take initiative, competitiveness, determination, resilience, hope, optimism and confidence have also been reported to influence community reintegration (Wood, Connelly & Maly, 2010; Walsh et al., 2015). Perceived loss of control has been reported to lead to feelings of self-consciousness, decreased confidence, low self-esteem and anxiety, which hinder participation in activities (Wood, Connelly & Maly, 2010; Walsh et al., 2015).

In addition to these personal characteristics, the meaning and value that individuals attach to activities also influences participation. For example, if working is perceived as very important, the person would be more motivated to return to work post stroke (Walsh et al., 2015). This is supported by Rhoda *et al.* (2015) who concluded that the inability to resume previous roles can lead to feelings of inadequacy and a resultant disinterest in or avoidance of previously meaningful activities. A decreased desire to participate in activities will irrefutably influence the levels of community reintegration a stroke survivor achieves.

2.5.3.2 Environmental factors

There are several environmental factors have been reported to hinder community reintegration (Walsh et al., 2015; Chimatiro & Rhoda, 2017; Govender et al., 2019).

In South Africa environmental factors that have been identified as barriers to community reintegration are in both the natural and built environments (Cawood & Visagie, 2015). Natural barriers are geographical in nature which include inaccessible terrain and long travel distances to health and other facilities (Maleka, 2010; Cawood & Visagie, 2015; Christiansen, Baum & Bass, 2015). While built environmental factors include narrow doorways, stairs, inaccessibly bathrooms, uneven pathways and disability unfriendly public buildings and services (Rhoda, Mpofu & De Weerdt, 2011; Cawood & Visagie, 2015; Christiansen, Baum & Bass, 2015). Two studies conducted in Rwanda (Urimubenshi & Rhoda, 2011) and Malawi (Chimatiro & Rhoda, 2017) identified similar environmental barriers to community reintegration post stroke in South Africa.

In the Eastern Cape, a more rural province in South Africa, stroke survivors have reported manoeuvring natural obstacles like uneven ground particularly in rainy weather a prominent barrier resulting in dependence on others for fear of falling (Cunningham & Rhoda, 2014). While structural obstacles in the built environment have been reported in the Western Cape such as curbs and stairs as well as inaccessible toilets (Cawood & Visagie, 2015; Scheffler & Mash, 2019), other obstacles include poor public transport (Kahonde, Mlenzana & Rhoda, 2010; Rhoda, Mpofu & De Weerdt, 2011; Cawood & Visagie, 2015), and the danger poor mobility poses due to gang violence in some areas (Cawood & Visagie, 2015).

The lack of accessible, disability-friendly transportation systems that limit independent community mobility is the most frequently reported environmental barrier. This has been reported in first world countries (Walsh et al., 2015), as well as African countries like Malawi and Rwanda (Urimubenshi & Rhoda, 2011; Chimatiro & Rhoda, 2017) and in several provinces in South Africa like the Western Cape (Kahonde, Mlenzana & Rhoda, 2010; Rhoda, Mpofu & De Weerdt, 2011; Cawood & Visagie, 2015) and in Gauteng (Ntsiea, van Aswegen & Lord, 2017). As can be seen, one of the predominant barriers to community reintegration are the constraints surrounding community and rehabilitation access (Walsh et al., 2015).

While literature reports barriers to community reintegration as being the constraints in the surrounding community and rehabilitation access (Walsh et al., 2015) some environmental factors can also be seen as facilitators to community reintegration. Environmental factors such as mobility assistive devices are reported to facilitate the process of community reintegration (Cunningham & Rhoda, 2014).

Equally important is the social environment that contributes to or hinder community reintegration of stroke survivors. Social environments, characterised by the practical and emotional support from family, friends and colleagues, encourage participation in meaningful activities and allows for autonomy and reciprocity (Walsh et al., 2015). Stroke support groups have been found to facilitate community reintegration (Cawood & Visagie, 2015). On the other hand, a lack of social support systems and services lead to social isolation and decreased community reintegration (Cawood & Visagie, 2015; Rhoda et al., 2015), over supportive families can lead to feelings of dependency and of being a burden, which may be perceived as a barrier to community integration (Cawood and Visagie, 2015; Walsh *et al.*, 2015).

Additional social barriers to community reintegration are negative community attitudes such as stigma (Urimubenshi & Rhoda, 2011; Chimatiro & Rhoda, 2017). Persons with neurological disabilities have been reported to be concealed by their families and socially excluded from participating in activities such as driving, participating in sport and family events or even getting married (Elliot et al., 2019). Similarly, stereotypical and negative attitudes towards persons with disability often decrease their chances for employment, therefore having a direct impact on successful community reintegration (Trani et al., 2020). Stigma is often found to be due to fallacies about disability rooted in the cultural or religious beliefs that exist in communities (Rohwerder, 2018).

In many communities, the cause of disability, including neurological conditions like stroke, is attributed to ancestral curses, wrong doings of parents, sin or the incorrect behaviour of the person who is disabled, supernatural reasons like demonic possession, witchcraft or punishment from God (Wegner & Rhoda, 2015; Rohwerder, 2018; Elliot et al., 2019). Moreover a person with a disability is often seen as less valued in the community (Wegner & Rhoda, 2015), due to their inability to contribute financially (Rohwerder, 2018). These misconceptions often lead to persons with neurological disabilities being stigmatized, especially in more rural communities, where the lack of knowledge regarding the diagnosis and lack of a potential cure

increases the shame associated with it (Elliot et al., 2019). Some stigma-related behaviour that has been reported are delays in seeking a formal diagnosis and medical treatment or struggling to get to a clinic due to taxi drivers being unwilling to pick up a person that is “cursed” (Wegner & Rhoda, 2015; Elliot et al., 2019).

Cultural beliefs also play an important role in how patients access and utilize rehabilitation services in South Africa (Wegner & Rhoda, 2015). Wegner and Rhoda (2015) found that worldviews regarding a person’s worth, the cause of disease and stigma together with low levels of health literacy can prevent patients from using available rehabilitation services. Often PwD will not comply with therapy and strategies to prevent further disability because it does not fit into their cultural understanding of health and disability, or they do not believe in the quality and effectiveness of the therapy. When people do not understand their condition they tend to think that the rehabilitation does not work (Wegner & Rhoda, 2015). To demonstrate, in rural South Africa 10-33% of patients go to a traditional healer before seeking western medical help, and 40-80% of patients combine their medical care with that from churches or traditional healers (Brainin, Teuschl & Kalra, 2007).

These culturally related beliefs have been reported to extend to the therapist/health care provider that are from the same cultural background, believing that this person cannot be as well qualified or capable as others (Wegner & Rhoda, 2015). Believing that therapy is ineffective, not applicable or that the therapist is incompetent contributes to stroke survivors to not continue accessing the rehabilitation services that could facilitate their community reintegration.

Consequently, stroke survivors often have decreased utilization of health care not only due to limitations in terms of the availability and accessibility of services but also due to cultural beliefs and health literacy and health care provider attitudes (Elliot et al., 2019). Moreover, this may be different in each community thus, family and cultural sensitivity is essential in any rehabilitation intervention (Whiteford & St-Clair, 2002).

Lastly, community reintegration can be influenced by the relationship between stroke survivors and their health care workers. Several facilitators and barriers have been identified relating to these relationships in the literature. Walsh *et al.* (2015) found that a positive relationship between a stroke survivor and their healthcare workers as well as an initial positive rehabilitation experience can lead to successful community reintegration. Similarly, in the Western Cape and

Eastern Cape, the social support and the assistance received from health professionals was reported as an environmental facilitator to community reintegration (Kahonde, Mlenzana & Rhoda, 2010; Cawood & Visagie, 2015). The assistance preferred by stroke survivors included receiving guidance on how to resume previous activities, access to community services as well as having the opportunity to practice activities at home with professional guidance (Walsh et al., 2015).

On the other hand, failures in the health worker-patient relationship, directly influence the levels of community reintegration achieved (Sofaer & Firminger, 2005). For the most part, the relationship-related barriers reported in literature are the lack of patient involvement during treatment as well as nature of and way information is provided to them. Patients have reported that during rehabilitation they were inadequately involved in determining the focus or outcome of treatment and often treatment was implemented without prior explanation of the procedures (Kahonde, Mlenzana & Rhoda, 2010; Walsh et al., 2015). On discharge, patients reported a lack of information was provided regarding support services (Kahonde, Mlenzana & Rhoda, 2010; Walsh et al., 2015), as well as guidance on how to manage challenges such as fatigue, access to transport, return to driving and going back to work (Walsh et al., 2015; Turner et al., 2019). As a result, patients reported feeling alone, abandoned, unprepared for discharge and often experienced a shortfall in continue therapy (Walsh et al., 2015; Turner et al., 2019).

However, when follow-up by health care professionals was ensured, stroke survivors reported that the appointments were medically focused and often neglected the provision of rehabilitation in line with holistic care (Turner et al., 2019). A study by Scheffler and Mash (2019) in rural Western Cape, reported that although most participants and their care givers were satisfied with the information received regarding accessing continued services, they reported dissatisfaction with the illness-related information provided as well as a lack of continued rehabilitation focused on achieving functional goals (Scheffler & Mash, 2019). The lack of adequate follow-up in the community care resulted in patient feeling unheeded, misunderstood and neglected (Scheffler & Mash, 2019). Dissatisfaction with health care directly influences community reintegration as client satisfaction has been linked to increased use of services, better client compliance and continuity of care (Ardey & Ardey, 2015).

2.5.3.2 Occupational factors

As mentioned previously, occupational therapists' skills in assisting patient to surmount the challenges they experience in engaging in activities in their communities makes them crucial team players in facilitating community reintegration for PwD such as stroke survivors (OTASA, 2015; Naidoo, Van Wyk & Joubert, 2017). One of the fundamental beliefs of occupational therapy is that for a person to be healthy they need to be able to participate in occupations that they find meaningful and purposeful (Christiansen, Baum & Bass, 2015) to promote motivation to engage.

Literature supports the use of occupation-based interventions to improve the ADL participation of stroke survivors with the strongest evidence for occupation-based intervention in the home setting and in in-patient settings (Wolf et al., 2015; Nielsen et al., 2017).

Occupation-focused intervention focuses on practicing activities and tasks for most of the session (Nielsen et al., 2017). This would include applying behaviour and cognitive strategies as well as making changes to the environment to improve stroke survivors' occupational performance in ADLs, IADLS and leisure activities that they find challenging (Nielsen et al., 2017) considering the need for assistive devices to improve participation and caregiver training (Govender et al., 2019). Nonetheless, for this intervention to be effective the stroke survivor and the therapist need to work together to set goals that the stroke survivor feels are beneficial to his or her recovery (Christiansen, Baum & Bass, 2015).

2.6 CONCLUSION

Through the review of the literature, it was found that there is a high prevalence of strokes in South Africa and in the Western Cape in particular. Stroke is a condition, which depending on its severity and associated disability, potentially has a major impact on person's ability to reintegrate into their communities following discharge from hospital. Poor reintegration is reported to have a significant influence on the QoL of stroke survivors experience.

It was established that community reintegration is best facilitated through rehabilitation that takes place in the community or in the home, but in the South African context several barriers to rendering these services have been identified. In addition to the context that stroke survivors find themselves in, literature highlighted both the intrinsic and extrinsic factors that also influence the levels of community reintegration stroke survivors achieve.

Furthermore, literature emphasises the important role that occupational therapy plays in facilitating the community reintegration of stroke survivors. Literature also highlighted some of the barriers and challenges that South African occupational therapist experience in providing this service, include their own understanding of their role on the primary platform and in the provision of UHC coupled with understanding of the barriers and facilitators that stroke survivors experience with community reintegration in the same area that they are servicing. Although multiple studies have been conducted on the barriers and facilitators that stroke survivors experience during community reintegration no literature could be found that explores the barriers and facilitators to community reintegration from the perspective of both stroke survivors receiving occupational therapy services and occupational therapists that provide services in the same area.

Previous studies have highlighted the importance of stroke survivors and occupational therapist's goals for intervention need to be aligned based on the stroke survivors perceived occupational needs associated with community transition. There are no studies available that specific to the Eastern Metro District (Eastern SD) that provide evidence for the occupational service delivery outcome of community reintegration to stroke survivors, nor that compares the barriers and facilitators to community reintegration as perceived by the service users and the service providers in this area. This gap is critical to effective service delivery as proposed by the NHI. This study hopes to address this gap. The following chapter will discuss the methodology used in this study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter describes the research methodology that was used to explore the community reintegration of stroke survivors one to three years post stroke, from the perspective and experience of stroke survivors as users of the community occupational therapy service and that of the occupational therapists as service providers. This chapter describes the study method used, the research site, research population and sampling method used. The data collection and data analysis are described, as well as the ethical considerations and the trustworthiness principles that were employed.

3.2 STUDY DESIGN

The researcher used a descriptive, qualitative study design to conduct this study (Creswell, 2014). A qualitative methodology allowed the researcher to collect data that would provide in-depth narratives from the participants so as to gain more insight into the individual meaning and complexity of community reintegration as experienced by stroke survivors as service users and the occupational therapists who rendered services in their area (Creswell, 2014). A descriptive phenomenological research approach was used so that the lived experience of community reintegration after a stroke could be described and interpreted from the perspective of stroke survivors and community occupational therapists (Creswell, 2014). It was anticipated that the qualitative methodology would identify critical practice issues using the PEOP model as an occupational therapy lens to analyse the narrative descriptions of both sets of role players in the process of community re-integration after stroke survivors have completed a short period of intensive in-patient rehabilitation (Daly et al., 2007).

Data were collected through semi-structured interviews. Interviews gave the researcher the advantage of collecting data even in situations where stroke survivors community reintegration could not be directly observed (Creswell, 2014). As the study took place during the COVID-19 pandemic, collecting data through semi-structured interviews allowed the participants to choose either a face-to-face interview or telephonic interview, to ensure compliance with the COVID-19 prevention regulations of the National Disaster Act. Most face-to face interviews took place in participants homes but one took place at the nearest clinic, as per each participants preference. Due to the specific inclusion criteria which limited the potential number of both

stroke survivors and occupational therapy participants (OTPs) that could be recruited, semi-structured interviews were chosen for data collection over focus groups. This decision was also influenced by the fact that individual interviews have been reported to generate more unique data items per individual than focus groups as well as requiring less participants, shorter periods for data collection and less time to transcribe and analyse the data (Guest et al., 2017). Noting that the study was done in partial completion of the researcher's master's degree, data had to be collected within the time constraints that the researcher had. It was however noted that focus groups are reported to allow more sensitive themes to emerge than individual interviews which could have impacted the richness of the data collected (Guest et al., 2017).

A constructivist world view was used to approach the data gathered as the research aimed at exploring understandings and insights from the participants experiences and perceptions of community re-integration following their stroke and on providing services for stroke survivors (Creswell, 2014). Therefore, interview questions were structured in an open-ended manner to achieve more in-depth answers and participants were given the option of using a language in which they were comfortable to express their views more freely about their community reintegration.

3.3 STUDY SETTING

The study took place in the Eastern SD of the Western Cape, South Africa. All the stroke survivor participants (SSPs) that were interviewed resided in this area and all the OTPs rendered services in this area.

The stroke participants interviewed had all received an average of 8 weeks in-patient rehabilitation at Western Cape Rehabilitation Centre (WCRC). This is the only public sector, specialised rehabilitation centre in the Western Cape that provides intensive, in-patient therapy to persons with physical disabilities. Only patients that have a long-term permanent disability and require a high intensity level of rehabilitation (4 to 6 hours per day) are admitted to WCRC (Western Cape Government, 2014a). During admission each stroke survivor has an allocated facility-based occupational therapist, physiotherapist and social worker that provides daily to weekly therapy. Should the participant required further multidisciplinary intervention they would be referred to a speech therapist, psychologist, or dietician. Referrals to WCRC are received from all levels of health care across the province, although not all stroke survivors in the

Western Cape are necessarily referred or admitted to WCRC (Cawood & Visagie, 2016; Western Cape Government, 2021a).

After completing their rehabilitation programme at WCRC, patients are then referred to their nearest CHC or Community Day Centre (CDC) for continued management. Most patients are discharged on an outcome level III (see Appendix A), indicating that the patients have achieved an acceptable level of independent functioning to return to his or her long-term residence (Western Cape Government, 2014a). However, patients may not yet be able to monitor their own health, manage their finances, move around safely in the community, participate in community and recreational activities, or return to work.

The Eastern SD, had an estimated population of 621 703 in the 2018-2019 census (Western Cape Government, 2018). Socio-economically, the area had an unemployment rate of 30%, with a 16% of households earning less than R4800 per annum and 20.5% living in informal dwellings. Approximately 88.3% of the population was dependent on the public health system (Western Cape Government, 2018). The Eastern SD was one of eight sub districts in the Cape Metro health district (Western Cape Government, 2018). All services were provided by two public health service providers, namely the Western Cape Government, known as the Metro District Health Services (MDHS) and the municipality of the City of Cape Town (CCT).

In the Eastern SD, the MDHS services consisted of six CDCs and two district hospitals while the CCT services consisted of one CDC, 10 clinics, one mobile clinic and one satellite clinic (Western Cape Government, 2018). In 2017, the area's total community multidisciplinary rehabilitation team consisted of three occupational therapists, four physiotherapists and one audiologist (excluding those employed by the two district hospitals) (Western Cape Government, 2018). At the time of data collection, the community multidisciplinary rehabilitation team remained the same except for an additional community service speech therapist.

This means that at community level there was one occupational therapist per 207 234 people, leaving services stretched very thin in the Eastern SD. Taking into account the high prevalence of stroke in the country (StatsSA, 2016), a high case load of stroke survivors in the Eastern SD can be assumed as no statistics were available regarding the number of stroke survivors that required services in the Eastern SD.

3.4 STUDY POPULATION

3.4.1 Source of participants

Data were collected from two populations.

- Firstly, mild to moderate stroke survivors that were one to three years post discharge from WCRC and lived in the Eastern SD.
- Secondly, from the MDHS community-based occupational therapists servicing the Eastern SD.

3.4.2 Sample selection

3.4.2.1 Stroke survivor participants

Purposive nonprobability sampling (Lavrakas, 2008) was used to select the SSPs, as the researcher intentionally invited participants that met the inclusion criteria to participate in the study. Purposive sampling has also been recommended for the selection of a small sample limited by geographical area, as with this study (Lavrakas, 2008).

A retrospective record review was completed of all the hospital admission records of stroke survivors that had been admitted to WCRC as in-patients from the 1st of January 2019 to the 1st of April 2021. This allowed the researcher to identify all stroke survivors that were one to three years post in-patient rehabilitation. All stroke survivors that did not reside in the Eastern SD of the Western Cape were excluded. The remaining 43 candidates were then contacted and invited to participate in the study. If they agreed to participate, verbal permission to access their medical folders was attained. When consent was obtained, all the medical folders were drawn and were reviewed.

Of these candidates all had received physiotherapy and occupational therapy and those with speech deficits had received speech therapy as well. Using the medical and MDT's professional records, referral letters and discharge reports in the medical folders the possible participants were filtered considering to the following:

- The Canadian Neurological Scale (CNS) was used to classify the severity of the initial neurological deficit, by scoring the patients according to the symptoms documented in the medical file on admission (Cote et al., 1986). This was conducted by the researcher

and allowed the researcher to identify stroke survivors who had a mild to moderate stroke and therefore a higher probability of recovery (Prabhakaran et al., 2008).

- Patients with severe cognitive impairments were excluded as poor cognitive functioning has been associated with achieving lesser levels of functional independence (Lim et al., 2018) and being a barrier to community reintegration (Walsh et al., 2015)
- Patients who had not achieved an outcome level III at discharge were excluded. The outcome level achieved on discharge is indicated in the patients discharge letter, found in the medical folder.

Thus, the criteria used to identify potential SSPs for the study are recorded in Table 3.1

Table 3.1 Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Participants: • with mild to moderate stroke classified according to the CNS scores (Cote et al., 1986), • who were one to three years post discharge from WCRC, • and who achieved an outcome level III on discharge according the rehabilitation outcome levels developed by Landrum, Schmidt and McLean (1995).	Participants: • that lived outside the Eastern SD of the Western Cape, • who had a severe stroke according to the CNS scores, • with expressive aphasia/ a communication disorder that hindered independently participating in an interview, • and who had severe cognitive fallout on discharge as noted in their medical record.

3.4.2.2 Study Sample and Size and Data Saturation

Typically the sample size in qualitative research is small (Creswell, 2014) and with research using a phenomenological approach, a sample size less than 20 has been frequently used as the sample size. Sample size is determined by the need to find the main variants within the approach (Gonzalez, 2009). Similarly, Hagman and Wutich (2017) found that in a relatively homogeneous groups, 16 or less interviews could be enough to identify collective themes.

Based on the above and Guest, Bunce and Johnson's (2006) view that data saturation can be achieved after the first twelve interviews as limited new phenomena arises after that, a sample size of 12 participants was chosen. However, interviews were conducted until data saturation was reached. Saturation is achieved when fresh data no longer reveals new insights (Guest, Bunce & Johnson, 2006; Creswell, 2014). To monitor this, a data saturation table was used

(see Appendix B) to keep track of participants responses and to determine when no new themes, categories, subcategories, or codes were emerging. Following the initial coding, the themes codes and subcodes were recategorized and renamed. The data saturation table was adjusted accordingly, and raw data were reviewed to ensure that saturation was indicated correctly.

3.4.2.3 Occupational therapy participants

Total population sampling (Lavrakas, 2008) was used to select the OTPs as there were only three occupational therapists servicing the Eastern SD of the Western Cape. Therefore, all three occupational therapists working in this area were invited to participate in the study.

3.5 DATA COLLECTION PROCESS

Data were only collected after obtaining ethical approval from the University of Witwatersrand Human Research Ethics Committee (Medical), clearance certificate number M190530, (see Appendix C) as well as the Western Cape DoH (see Appendix D). The Western Cape DoH required that each facility give approval prior to ethical clearance certificates being issued. This included WCRC as well as the three clinics that employed the OTPs (see Appendix D). When approval was received, the data collection procedure was commenced with the respective participants, although the COVID-19 pandemic delayed data collection.

The study data were collected using a demographic questionnaire and interview guide used in the semi structured interviews.

3.5.1 Demographic profile of participants

Participant demographic data were collected through questionnaires. The researcher developed two different demographic questionnaires. One for the SSPs (see Appendix E) and one for the OTPs (see Appendix F).

The SSPs completed the questionnaire as part of the interview and all OTPs completed it electronically prior to the interview.

- The stroke survivor participant demographic questionnaire included 5 personal questions, 2 questions regarding employment and 4 questions regarding medical information.

- The occupational therapy participant demographic questionnaire consisted of 5 personal questions and 3 questions related to the patient profile of their services.

3.5.2 Interview guide regarding community reintegration

Semi-structured interview guides were developed for the semi-structured interviews. As with the demographic questions, two sets were developed, one for the SSPs (see Appendix G) and one for the OTPs (see Appendix H).

The semi-structured interview guide consisted of a number of open-ended questions on topic areas, with predetermined prompts to ensure consistency during the interviews (Creswell, 2014). The research objectives and current literature were consulted to develop the interview guides (Creswell, 2014). An interview protocol was used to structure the interview format which could be used in both face-to face or telephonic interviews. The protocol included headings, instructions that the researcher needed to follow to ensure consistency with interviews, followed by the interview questions and prompts (Creswell, 2014). At the end a final thank you statement was made to acknowledge the time that the participant had given.

The questions and prompts were based on the CHART measurement tool that measures PwDs social participation and takes into account aspects such as cognitive independence, physical independence, mobility, social integration, occupational and economic independence (Corrigan & Bogner, 2004) as well as the Reintegration to Normal Living Index (RNLI) guidelines which covers variations of mobility, daily functioning and perception of self (Gretschel, Visagie & Inglis, 2017). Prompts for possible barriers and facilitators used the WHO definition of environmental facilitators and barriers in the ICF (Organisation, 2001).

The stroke survivor participant interview guideline consisted of seven open ended questions each with a number of prompts. Question 1 and 2 explored what activities the participants were involved with prior to their stroke and how their participation changed after their stroke and the influence on their community integration. While Question 1 and 2 focussed more on gaining background to the stroke participants activity participation prior to their stroke, Questions 3 to 7 addressed community reintegration. Question 3 and 4 explored the perceived barriers and facilitators to participation in their communities. Question 5 and 6 explored what the participant had found useful or non-useful from their in-patient rehabilitation period. Lastly, question 7

asked if the participants had continued with any rehabilitation after discharge from WCRC and explored the reasons.

The OTP interview consisted of four open-ended questions with similar prompts as with the SSPs interviews. The first question explored what the occupational therapists' perceptions and experiences of how stroke survivors reintegrate into their communities in the area they serviced. The second question explored the challenges experienced in facilitating the reintegration of stroke survivors into their communities. The third and fourth question explored the perceived factors that influence to the patient's ability to reintegrate into their community.

As the Western Cape has three official provincial language, namely English, Afrikaans and isiXhosa (Western Cape Government, 2021b) the demographic questionnaires and the interviews were conducted in the language of the participants choice. The researcher conducted interviews in English and Afrikaans, and with the one participant that was isiXhosa speaking, one of clinic's CHWs assisted with the translation. This was to ensure ethnic inclusiveness of the sample as far as possible.

During the face-to-face interviews, observations of the physical and social setting of the participant were noted. This provided the researcher the opportunity to take into account the influence that the physical environment had on the participant (Mulhall, 2003). Field notes were taken to document these observations and Mulhall's (2003) suggested scheme to document people, organisational and structural features was used.

3.5.3 Pilot interview

An interview process was piloted with an occupational therapist known to the researcher, and who had experience in working in the community. This gave the researcher the opportunity to practice gathering rich and thick data, ensure that the questions would be easily understood and were appropriate to the study objectives. No major challenges were encountered during the pilot interview and no changes were made to the interview guideline. No pilot interview took place with SSPs due to the limited access to participants.

3.5.4 Recruiting of stroke survivor participants

Following the ethical approval and permission from the Western Cape Health department the recruitment process of the SSPs was followed as per Figure 3.2.

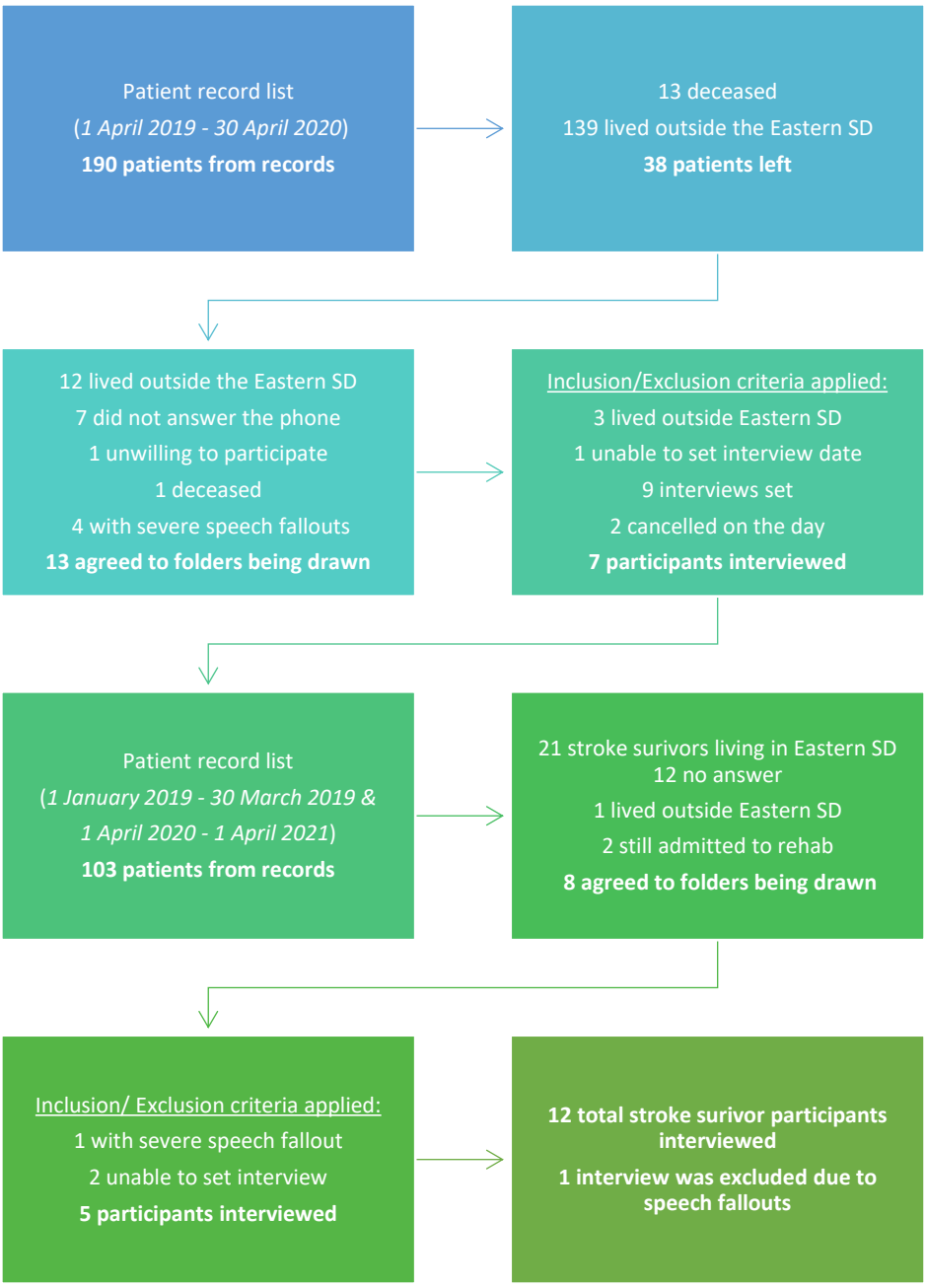


Figure 3.1 Data collection process

A request was submitted to WCRC's rehabilitation manager to obtain a record of all the stroke survivors discharged from the period of 1st of January 2019 to 30th of April 2020 (one year post rehabilitation). Due to insufficient potential participants, additional records were drawn for the periods between the 1st of January 2019 until the 30th of March 2019 and from the 1st of April 2020.

The patient records were provided by WCRC's rehabilitation manager via email and were received as an excel sheet which included the patient's folder number, surname, first name, ethnic group, address, and mobile phone number. On review, it was found that many of the addresses and telephone numbers were incorrect. As the researcher was employed at WCRC during the study period, the researcher then made use of clinicom, the booking and billing system used at WCRC, to obtain the correct addresses and phone numbers with the permission of WCRC's rehabilitation manager. The potential participant list was then filtered to exclude all participants that lived outside the Eastern SD, leaving 59 candidates. All 59 of the remaining potential candidates were then called to request verbal permission to access their medical records and identify possible participants according to the inclusion/exclusion criteria.

A total of 21 stroke survivors agreed to have their folders reviewed and analysed based on the MDT notes on admission to classify the severity of the strokes according to the CNS scores and the notes on discharge including the discharge reports to determine the other inclusion/ exclusion criteria. The physiotherapy, occupational therapy and speech therapy medical notes were primarily used. In total 17 stroke survivors met the inclusion criteria.

These 17 potential participants were contacted telephonically and invited to take part in the study. The procedures and goals for the research study were explained according to the approved information sheet (see Appendix I). Due to the COVID-19 pandemic restrictions, stroke survivors who consented to participate were given the option to have the interviews telephonically or face-to-face in their homes or at the nearest clinic at a convenient date.

Prior to the interviews, the participants were invited to choose their language of preference. Again, the information sheet (see Appendix I) was provided, and the participant was given the opportunity to read it and ask any questions. If the participant confirmed participation in the study, the participant consent sheet (see Appendix J) and consent form for audio recordings (see Appendix K) were signed. This was then followed by completing the Stroke Participant demographic questionnaire (see Appendix E) followed by the semi-structured interview using the Stroke Participant Interview Guideline (see Appendix G). During the interview, the researcher made use of a smartphone for the audio recordings. For the telephonic interview, the information sheet was read over the phone to the patient and verbal consent was obtained and recorded. One interview that took place at the nearest clinic and a rehabilitation care worker assisted with the translation process.

3.5.5 Recruiting of the occupational therapy participants

All three community occupational therapists servicing the Eastern SD were contacted via email using the Metro District Health Service occupational therapy resource list and invited to participate in the study. The information sheet for OTPs detailing the study (see Appendix L) was provided. As soon as the therapists consented to participate, and language preference of the interview was determined, an interview date was set. The occupational therapy participant demographic questionnaire (see Appendix F), participant consent sheet (see Appendix J) and consent form for audio recordings (see Appendix K) were emailed and participants were requested to complete and sign the documents electronically prior to the interview. Only two of the three therapists consented to participate in the study. Both requested that the interviews take place remotely, one via Microsoft teams and one via a telephonic call. The occupational therapy participant interview guideline (see Appendix I) was used to facilitate these interviews.

All the interviews were digitally recorded and transcribed verbatim. As all the interviews took place in English, no translation was required. During the research process the researcher kept a personal reflective journal to document how the researcher's life experiences, and professional biases may influence the data collection and analysis of observations made.

3.5.6 Trustworthiness of data

Several principles of trustworthiness were used to ensure the credibility of the data through ensuring triangulation, credibility, dependability, transferability, and confirmability.

Triangulation of data methods was ensured by using different means to collect data (Krefting, 1991). This was achieved by triangulating the findings of the SSPs interviews with that of the findings from the two OTPs' interviews (Noble & Heale, 2019).

Confirmability was ensured by confirming the results through peer-reviewing. The researcher's codebook was reviewed by the supervisor to check for bias. Member checking with SSPs was impossible on a practical level.

Credibility was ensured by recording a clear trail of evidence regarding the study. (Fereday & Muir-Cochrane, 2006). Recording all the interviews that took place and transcribing them verbatim. All transcriptions were double checked to ensure that they were transcribed correctly (Creswell, 2013). A detailed description was provided of the participants and the data collection process. The code books used during data analysis were provided as well as a description of

the coding process. Transcripts and proposed codes were also revised with the research supervisor as a co-coder (Creswell, 2014). Bracketing was applied as recommended by Chan, Fung and Chien (2013) by making use of semi-structure interviews with open-ended questions and pre-prepared probes. This allowed the researcher freedom to probe new information that arose during the interview that had not necessarily been considered prior to the interview. Lastly, reflexivity was applied during the data analysis period, where the researcher took into account her own background as a health care worker and how this could have influenced how the data was organised, studied and analysed (Krefting, 1991; Chan, Fung & Chien, 2013).

Transferability and dependability was ensured by presenting enough descriptive data to allow comparison in future studies (Krefting, 1991) and a clear and detailed description of the research methods and processes used was provided (Creswell, 2014). This was provided by recording the details of the data collection process as well as a reflective journal of all the decisions made, actions taken, meetings held and how these influenced the research path (Mulhall, 2003).

3.6 ETHICAL CONSIDERATIONS

The study protocol and title were approved by the Faculty of Health Sciences Graduate Studies Committee (see Appendix M) as well as by the Human Research Ethics Committee (medical) of the University of Witwatersrand (see Appendix C). Further approval was also received from the Western Cape DoH for each health facility (see Appendix D) where the participant's medical files were accessed as well as where the OTPs worked.

Throughout the study several ethical principles were adhered to as outlined in the Health Professions Council of South Africa's General Ethical Guidelines (HPCSA, 2016).

The principle of non-maleficence and beneficence (HPCSA, 2016) was adhered to by ensuring that no risk of harm could come to the participants through their participation in the study. Questions were asked with sensitivity and in a non-judgemental manner. The only risk identified was that participants could experience emotional difficulty to discuss their experiences. Participants were informed that they did not need to share anything that they were not comfortable in sharing and support was expressed if they were observed to be distressed. If the distressed observed was significant, the participant would be referred to the psychologist at the nearest clinic for emotional support.

The principle of autonomy (HPCSA, 2016) was safeguarded by choosing participants that had minimal speech deficit and could participate independently in the interviews. When participants were invited to participate in the study they were provided with information regarding confidentiality, the purpose of the study, the population criteria, and their right to withdraw at any stage of the study was emphasised giving them autonomy about their participation. For participants with emails, the information sheet (see Appendix I and L) was emailed otherwise the content was explained telephonically and then repeated on the day of the interview where participants were given the opportunity to read the information sheet prior to the interview and decide if they are still willing to participate. If participants struggled to read, the information and consent sheets were read out loud in the participants language of preference.

The principle of confidentiality (HPCSA, 2016) was ensured by contacting all stroke survivors telephonically to request permission to access their medical folders and record the information on an excel sheet when permission was granted. Furthermore, when participants had been recruited, a number was allocating to a person's name on the data sheet. Data was anonymised by refraining from using names during the interview and where the participant used his own name, during the transcription this was replaced with or the participant's number. Cell phone numbers remained private and were not given to any other parties and no names were mentioned when writing up the results. Due to the small OTP sample size complete confidentiality could not be guaranteed and participants were informed of this in the information sheet.

Participants were treated with respect and dignity and during interviews by addressing them formally, ensuring that they felt comfortable and as far as possible putting them at ease. Participants were assured that they were under no obligation to share information that they were uncomfortable with sharing and when indicated so, the researcher moved on to the next question. The researcher made sure that the participants gave informed consent by providing them with the information sheets and consent forms in their home language and if it was not in their home language, a translator was used. All the information regarding the study was reported in layman terms for the SSPs and the researcher, supervisor and ethic committee contact details were included should the participant require any further information.

3.7 DATA MANAGEMENT

During the process of data collection, all files with the participant's information were kept in a separate encrypted file on a password protected computer. Field notes taken during the interviews were kept in a file to which only the researcher had access. Audio recordings were removed from the smartphone used after each interview and transferred to the allocated encrypted file on the researcher's computer.

The confidentiality of the transcribed interviews was ensured by the researcher and the transcriber having signed a confidentiality and non-disclosure agreement. All files were named according to the participant's allocated number and all other identifying information such as names and location of the interview was removed. All files were transferred via a secure programme, WeTransfer (WeTranser, 2021). After the transaction took place the audio files were automatically deleted from WeTransfer.

In compliance with the Protection of Personal Information Act 4 of 2013 (POPIA) (*Protection of Personal Information Act, No. 4 of 2013*, 2013) and the ethical rules regarding research from the Health Professional Council for South Africa (HPCSA, 2016), permission was obtained from the Western Cape DoH as well as WCRC to access the contact details of stroke survivors that had been admitted over a certain period. In compliance with Section 5 and 18 of the POPIA (*Protection of Personal Information Act, No. 4 of 2013*, 2013), possible candidates were contacted telephonically, and permission was requested to access the information in their medical folders. They were also informed regarding what information was required from their medical folders, the purpose of the information collected in the context of the study as well as the name of the researcher and the university of affiliation. In compliance with Section 14 of the POPIA (*Protection of Personal Information Act, No. 4 of 2013*, 2013), after concluding the study all the records provided by WCRC of stroke survivors discharged during a certain period were destroyed. This was done by deleting the files permanently from the researcher's computer.

In accordance to the Health Professions Council of South Africa ethical guidelines for health research, all data including the audio recordings will be stored up to 6 years in the absence of the publication of the research (HPCSA, 2016). All participants were informed regarding this in the information sheet as well as at the end of their interview. According to Section 14 (*Protection of Personal Information Act, No. 4 of 2013*, 2013) of the POPIA, record of personal information may be retained for longer periods for research purposes if the responsible party has ensured

that safety measures have been set in place so that the data cannot be used for some other purpose. Therefore, all files were stored on an encrypted computer within a locked folder that required a password.

3.8 DATA ANALYSIS

After the recruitment process, 12 interviews were completed with SSPs. Stroke survivor participant 5's interview was excluded due to a severe speech deficit that had not been indicated in the medical folder, leaving 11 interviews to be analysed. Two interviews were conducted with the OTPs as the third occupational therapist was unwilling to participate in the study.

3.8.1 Demographic data analysis

The demographic information was analysed descriptively using frequencies. Analysis was conducted by the researcher and reviewed by the supervisor.

3.8.2 Phenomenological analysis

The data analysis of the interviews was performed using concept analysis (Sandelowski & Barroso, 2003; Creswell, 2014). By initially using concepts and themes in an interpretive manner instead of just ordering portions of data, the researcher could use the concepts and themes that emerged to illuminate the perceptions and experiences that emerged (Sandelowski & Barroso, 2003). and then to Each of the two data sets were analysed separately and then both were compared to identify similarities and differences. The MAXQDA software was used for the data analysis (MAXQDA, 2022), and the licence was obtained through the University of Witwatersrand Faculty of Health Sciences.

During inductive data analysis, the PEOP model (Christiansen, Baum & Bass, 2015) was used as a theoretical framework to identify and structure the themes, categories, and subcategories.

The PEOP model is an occupational therapy model that considers the interaction between the person, the environment and the occupation that is being performed and how these factors interact and influence occupational performance. The model explains that occupational performance is determined three main components. Firstly, the person's intrinsic personal factors such as his/her psychological, cognitive, physiological, and neuro-behavioural abilities as well as his spirituality. Secondly, the facilitators or barriers provided by the environment such

as social support and social capital, social determinants, culture, education and policies, physical and natural environment, and assistive technology. Lastly, it considers the occupations that the person performs and is required of him/her which includes activities, tasks and roles (Christiansen, Baum & Bass, 2015). The following diagram (see Figure 3.2) was used to name the categories and subcategories used.

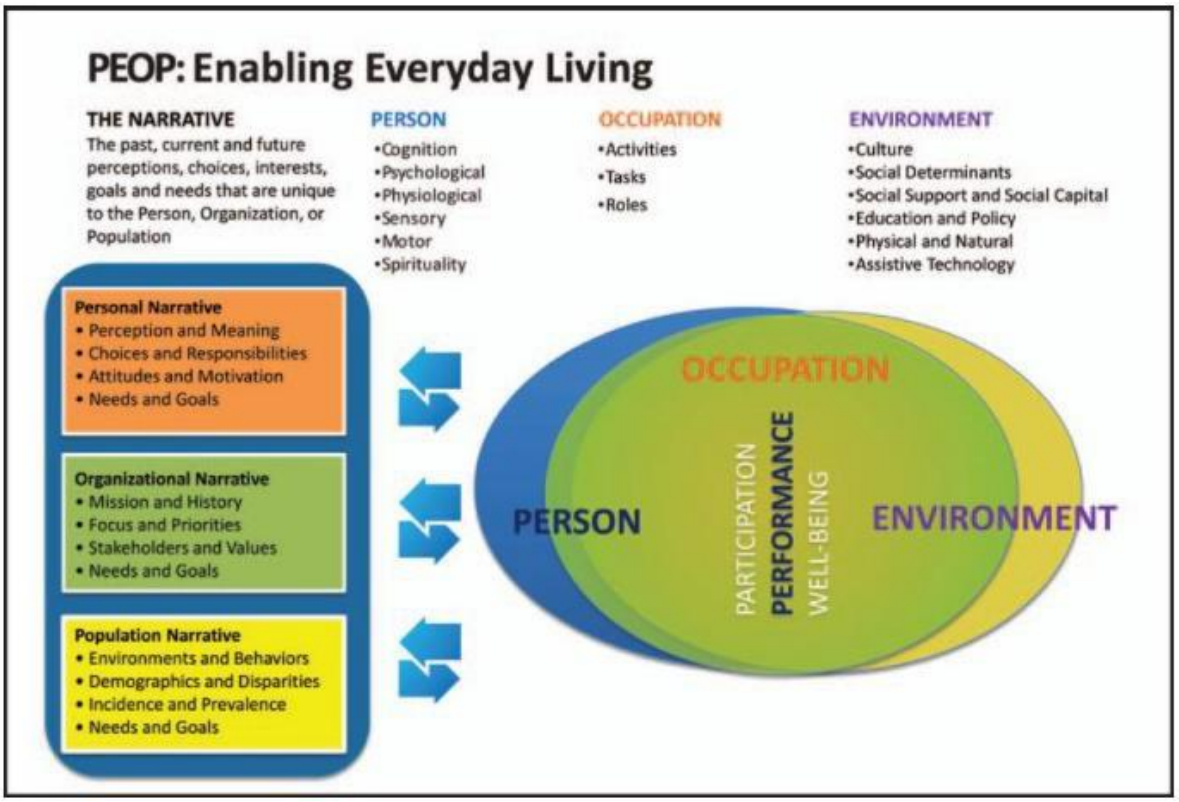


Figure 3.2 The PEOP model (Christiansen, Baum & Bass, 2015)

This model was chosen as it allowed the researcher to categorise barriers and facilitators according to intrinsic and extrinsic factors and then to categorise participants experiences and perceptions of their occupational performance base on the occupations and their perceived performance related to their community reintegration. Additionally, it provided an occupational therapy lens for the categorisation.

Figure 3.3 provides a diagrammatic representation of the process followed when data were analysed.

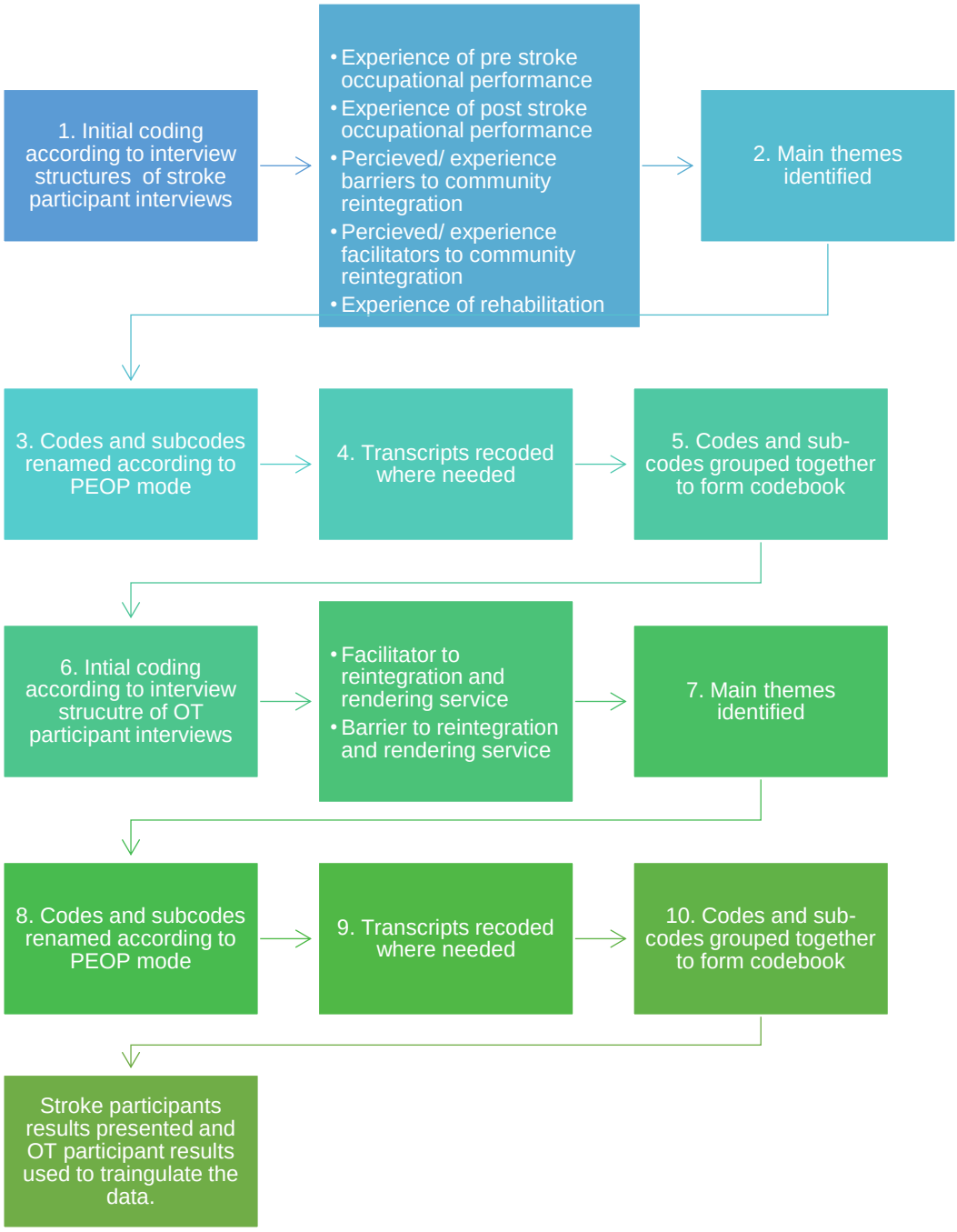


Figure 3.3 Flow diagram of the analysis process

3.9 CONCLUSION

The study design, setting, population and data collection tools used have been presented in this chapter. The procedures of data collection, recording and the analysis have been described, as well as the ethical consideration that were considered. The results of the statistical analysis will be further discussed in Chapter 4.

CHAPTER 4: RESULTS

The findings of the study will be reported in this chapter. Firstly, the data saturation will be reported and then the findings from the interviews will be reported in two parts. Part one will describe the demographic profile of the SSPs and OTPs. Part two will report on the qualitative findings of the 11 semi-structured interviews with stroke survivors. Due to only two OTPs being included in the study their findings will be used to triangulate the findings of the SSPs.

4.1 DATA SATURATION

4.1.1 Data saturation of stroke survivor participants

Fourteen SSPs interviews were scheduled of which two cancelled on the day. Therefore, 12 SSP interviews were completed, and 11 interviews were analysed. Nine interviews took place in participants' homes, two telephonically and one at the participant's nearest clinic. Stroke survivor participant five's interview was completed but was excluded following analysis, due to insufficient depth of the data collected.

Data saturation for SSPs was achieved when no new perceptions, experienced, barriers or facilitators emerged during the interview process. Three tables were used to record the responses of each SSP during the initial data analysis. This enabled the researcher to keep track of the frequency of SSPs' responses. The data saturation tables can be seen in Appendix B. The last new code that emerged was identified by SSP 9. To ensure data saturation, three more interviews were conducted, but no new codes emerged.

4.1.2 Data saturation of occupational therapy participants

Three occupational therapists were invited to participate in the study but only two consented. As only two interviews were conducted with the OTPs, the codes that emerged had a low frequency of responses and thus the data was not saturated. Since the OTP data was not saturated it was decided to use the OTP data to triangulate the findings of SSPs, as proposed by Noble and Heale (2019).

4.2 DEMOGRAPHIC PROFILE OF PARTICIPANTS

4.2.1 The stroke survivor participants

The ages of the SSPs ranged from 32 to 68 years old with a mean age of 56 years and most of the participants being in their 60s (n=6; 54.5%) (see Table 4.1. Of the 11 SSPs that took part in the study, 64% (n=7) were male and most (n=8; 72.75%) were married. The majority were Afrikaans speaking (n=10; 90.9%) with the exclusion of one SSP whose home language was isiXhosa. As can be seen in Table 4.4 all participants lived in the context of their family.

Table 4.1 Stroke survivor participants: demographic information

NAMES	AGE	GENDER	MARITAL STATUS	LIVING WITH	HOME LANGUAGE
SSP 1	67 yrs.	M	Married	Partner & children	Afrikaans
SSP 2	32 yrs.	F	Never married	Grandparents, sister, cousin, and daughter	Afrikaans
SSP 3	51 yrs.	M	Never married	Mother	Afrikaans
SSP 4	60 yrs.	F	Married	Partner, children, and grandchildren	Afrikaans
SSP 6	57 yrs.	M	Married	Partner & children	Afrikaans
SSP 7	62 yrs.	F	Widow	Children and grandchildren	Afrikaans
SSP 8	62 yrs.	M	Married	Partner	Afrikaans
SSP 9	51 yrs.	M	Married	With family	Afrikaans
SSP 10	68 yrs.	M	Married	Children and grandchildren	Afrikaans
SSP 11	60 yrs.	M	Married	Partner, children, and grandchildren	Afrikaans
SSP 12	48 yrs.	F	Married	Partner & children	isiXhosa

As seen in Table 4.2, most of the participants had an education level lower than high school (n=10; 90.9%) except for one participant who had completed grade 12. The majority (n=10; 90.9%,) of the SSPs had some form of employment prior to their stroke, except for one participant who was unemployed and not looking for work at the time of his stroke. In contrast, only 9% (n=1) of the cohort were able to return to work and only on an informal basis. Most SSPs (n=7; 63.6%) reported not being able to work due to their disability and the remaining (n=2; 18,2%) participants had retired. All were in receipt of a social grant, either a disability grant (n=8; 72.7%) or state pension (n=2; 18,2%).

Table 4.2 Stroke survivor participants: employment information

NAMES	LEVEL OF EDUCATION	EMPLOYMENT PRE-STROKE	EMPLOYMENT POST STROKE	DISABILITY GRANT / PENSION
SSP 1	< High school	Permanently employed	Retired	State Pension
SSP 2	< High school	Permanently employed	Informal worker	Disability Grant
SSP 3	Highschool/ equivalent	Informal worker	Disabled, unable to work	Disability Grant
SSP 4	< High school	Permanently employed	Disabled, unable to work	Disability Grant
SSP 6	< High school	Informal worker	Disabled, unable to work	Disability Grant
SSP 7	< High school	Unemployed, not looking for work	Retired	State pension
SSP 8	< High school	Self-employed	Disabled, unable to work	Disability Grant
SSP 9	< High school	Unemployed, not looking for work	Disabled, unable to work	Disability Grant
SSP 10	< High school	Contract employment	Retired	No
SSP 11	< High school	Self-employed	Disabled, unable to work	Disability Grant
SSP 12	< High school	Self-employed	Disabled, unable to work	Disability Grant

As can be seen in Table 4.3, the number of strokes that participants had survived varied from 1 to 5 with most (n=7; 63.6%) suffering a single stroke. On average the SSPs had their stroke 2 yrs. 2 months prior to the time of the interview and were on average 1 year 10 months post discharge from WCRC. On average all the SSPs (n=11) had been admitted to hospital for 4 weeks and two days in the acute stage following their stroke and for in-patient rehabilitation at WCRC for 7 weeks and 5 days, with an average of 2.9 months away from home (see Table 4.3).

Table 4.3 Stroke survivor participants: medical information

PARTICIPANTS	NUMBER OF STROKES	YEARS POST STROKE	YEARS POST WCRC REHAB	ACUTE ADMISSION PERIOD IN WEEKS	WCRC ADMISSION PERIOD IN WEEKS	TOTAL TIME AWAY FROM HOME IN MONTHS
SSP 1	5	1 yr. 3 mos.	1 yr. 2 mos.	12 wks.	5 wks.	> 4
SSP 2	1	1 yr. 11 mos.	1 yr. 8 mos.	3 wks. 1 day	9 wks. 3 days	> 3
SSP 3	1	1 yr. 10 mos.	1 yr. 8 mos.	4 wks.	6 wks. 3 days	> 2
SSP 4	4	1 yr. 9 mos.	1 yr. 5 mos.	12 wks.	13 wks.	> 6
SSP 6	1	1 yr. 10 mos.	1 yr. 8 mos.	> 4 wks.	2 wks. 2 days	> 1
SSP 7	1	2 yrs. 2 mos.	1 yr. 10 mos.	> 2 wks.	9 wks. 4 days	> 2
SSP 8	1	2 yrs. 8 mos.	2 yrs. 4 mos.	6 days	8 wks. 4 days	> 3
SSP 9	1	2 yrs. 6 mos.	2 yrs. 4 mos.	> 4 wks.	7 wks. 1 day	> 2
SSP 10	1	2 yrs. 8 mos.	2 yrs. 5 mos.	> 1 wk.	7 wks.	> 2
SSP 11	2	2 yrs. 10 mos.	2 yrs. 4 mos.	> 4 wks.	9 wks. 3 days	> 3
SSP 12	2	2 yrs. 7 mos.	2 yrs. 2 mos.	> 1 wk.	7 wks. 1 day	> 2
Average	1.8	2 yrs. 2 mos.	1 yr. 10 mos.	4 wks. 2 days	7 wks. 5 days	> 2.9

Furthermore, as seen in Table 4.4 most SSPs had a right sided stroke with left hemiplegia (n=6; 54,5%) with the remaining SSPs having a left sided stroke with right hemiplegia (n=4; 36,4%)

or a posterior cerebellar stroke (n=1; 9,1%). As presented in Table 4.4, the most prevalent comorbidities were hypertension (n=10; 90,9%), diabetes mellites (n=6; 54,4%) and increased cholesterol (n=5; 45,5%). Other mentioned comorbidities included gout, heart complications, dyslipidaemia, arthritis, chronic obstructive pulmonary disease, increased body mass index, smoking and the use of alcohol.

Table 4.4 Stroke survivor participants: nature of stroke, comorbidities, and outcome levels achieved

PARTICIPANTS	TYPE OF STROKE	COMORBIDITIES				CNS SCORE	OUTCOME LEVEL ACHIEVED ON DISCHARGE
		HPT	DM	CHOL	OTHER		
SSP 1	Left infarct, right hemiplegia	x	x			6.5 (moderate)	Level 3
SSP 2	Left infarct, right hemiplegia	x		x		9.5 (mild)	Level 4
SSP 3	Posterior inferior cerebellar artery territory infarct, Wallenberg Syndrome	x			Gout, ↑ BMI	9.5 (mild)	Level 4
SSP 4	Left MCA infarct, hyperdense right MCA infarct, right hemiplegia	x	x	x	Mitral valve replacement, on warfarin	6.5 (moderate)	Level 3
SSP 6	Right MCA infarct, left hemiplegia	x			Smoker, dyslipidaemia arthritis, atrial fibrillation	5 (moderate)	Level 3
SSP 7	Right infarct, left hemiplegia	x	x	x		8.5 (mild)	Level 4
SSP 8	Right infarct, left hemiplegia, expressive aphasia	x	x		Ischaemic heart disease	6 (moderate)	Level 4
SSP 9	Left infarct, right hemiplegia,	x				8 (mild)	Level 3
SSP 10	Right MCA infarct, left hemiplegia				Smoker, alcohol user	6.5 (moderate)	Level 3
SSP 11	Right infarct, left hemiplegia, dysarthria	x	x	x	COPD, smoker	4.5 (moderate)	Level 3
SSP 12	Right MCA infarct, left hemiplegia, expressive aphasia, left facial palsy	x	x	x	↑ BMI	6.5 (moderate)	Level 5

Table 4.7 Key: Stroke Survivor Participant (SSP), Middle Cerebral Artery (MCA), Hypertension (HPT), Diabetes Mellitus (DM), Increased Cholesterol (CHOL), Body Mass Index (BMI), Chronic Obstructive Pulmonary Disease (COPD)

4.2.2 Demographics of the occupational therapy participants

Two occupational therapists participated in the study. As can be seen in Table 4.5 both were young and female. Both had been employed at their current clinic longer than a year and reported having an interest in the field of neurology. Both had previously worked in the public sector, one in a secondary level hospital in the Western Cape and the other in a tertiary level hospital in the Northern Cape.

Table 4.5 Occupational therapy participants: demographic information

PARTCICPANTS	AGE	GENDER	PREVIOUS EMPLOYMENT HISTORY (TYPE, PLACE, LEVEL OF CARE)	PERIOD OF CURRENT EMPLOYMENT	AREAS OF INTEREST
OTP 1	27 yrs.	F	DoH occupational therapist in the Western Cape at Secondary Healthcare Level	> 1 yr.	Neurology
OTP 2	30 yrs.	F	Community service in Northern Cape at Tertiary Level	> 1 yr.	Neurology

Table 4.8 Key: Occupational Therapy Participant (OTP), Department of Health (DoH)

As can be seen in Table 4.6 both OTPs saw stroke survivors on a weekly basis although OTP 2 reported a 30 % higher percentage of stroke survivors in her workload than OTP 1. Both OTPs reported most stroke survivors were referred during the sub-acute phase of recovery. Likewise, both OTPs reported seeing stroke survivors at the clinic or at home and treatment was mainly individual during home visits. Participant two reported also seeing stroke survivors as part of an exercise group.

Table 4.6 Occupational therapy participant: stroke service information

NAMES	HOW REGULARLY DO YOU SEE STROKE SURVIVORS	% OF PATIENT LOAD ARE STROKE SURVIVORS	STAGE OF RECOVERY STROKE SURIVORS ARE REFERRED			WHERE SERVICES ARE PROVIDED	TYPE OF STROKE SERVICE PROVIDED
			ACUTE (1 DAY- 2 WKS)	SUB-ACUTE (3 WKS-6 MOS)	CHRONIC (>7 MOS)		
OTP 1	weekly	40%	5%	90%	5%	Clinic & home	Individual & Home visits
OTP 2	weekly	70%	0%	70%	30%	Clinic & home	Individual, Exercise Group and Home Visits

Table 4.9 Key: weeks (WKS), months (MOS)

4.3 FINDINGS FROM THE INTERVIEWS

Three main themes emerged from the interviews with the SSPs: changes experienced in occupational performance, barriers to community integration and facilitators that assisted community integration. Similarly, two main themes emerged from the interviews with the OTPs: barriers to providing a service that of community reintegration to stroke survivors and facilitators to providing a service that of community reintegration to stroke survivors which was consistent with the themes 2 and 3 of the SPPs.

Findings that emerged within each theme from the interviews with the SSPs will be presented and then the OTP responses will be used to triangulate the results. In line with the study's

objectives, OTP responses only pertained to theme two and three and therefore no OTP responses were used in Theme 1.

4.3.1 Theme 1: Changes experienced in occupational performance

Theme 1 emerged as the changes that the SSPs had perceived and experienced in their occupational performance since their stroke. All SSPs had experienced changes in what they were able to do.

> "No look, now I have to go in a wheelchair. Other days [before] I walked, walked myself, ran." [SSP 1]

> "It did, it was a little different. Look I am not strong enough yet, not strong enough yet to do many things." [SSP 2]

Table 4.7 details the categories and subcategories that emerged from the inductive reasoning used to conceptualise the participants experiences and perception of these changes using the lens of the PEOP model (Christiansen, Baum & Bass, 2015).

Table 4.7 Theme 1 Changes experienced in occupational performance

THEME 1	CATEGORIES	SUB-CATEGORIES
Changes experienced in occupational performance	Changes due to Personal Factors	Physiological Changes
		Neuro-behavioural Subsystem Changes
		Cognitive Changes
		Spiritual Changes
		Psychological Changes
	Changes due to Environmental Factors	Social Support
		Social and Economic Systems and Policies
		Cultural Values and Beliefs
		Physical and Natural Environment
		Assistive Technology
	Changes within Occupational & Performance Factors	Changes in the structure of activities
		Changes in roles

Three categories emerged from this first theme: changes due to personal factors, changes due to environmental factors and changes within occupational and performance factors which all contributed to their experience of altered occupational performance.

4.3.1.1 Changes due to personal factors

Changes in intrinsic personal factors was linked to the perception and experience that the stroke(s) the SSPs had suffered had influenced the way their body functioned and responded when they wanted to engage in occupations.

> "Look I could not go back, I could not go back to my work because of my stroke that I had, because many things in my body are different, my body is different now." [SSP 2]

In accordance with the PEOP model (Christiansen, Baum & Bass, 2015), the findings that emerged were divided into five subcategories representing the internal aspects of the human system that influence occupational performance as can be seen in Table 4.8.

Table 4.8 Personal factor changes

THEME 1	CATEGORIES	SUB-CATEGORIES	CODES
Changes experienced in occupational performance	Changes due to Personal Factors	Physiological Changes	Limited occupational performance due to a loss of endurance and strength
		Neuro-behavioural Subsystem Changes	Changes in occupational performance inside and outside home due to a loss of mobility
		Cognitive Changes	Increased dependence on family and friend's due residual cognitive changes
		Spiritual Changes	Questioning belief system and disappointment in spiritual support vs finding strength in it
		Psychological	Feelings of frustration, bitterness, disappointment, shame
			Difficulty to accept loss of function and worrying about future
			Resignation to fate

Physiological changes

In the PEOP model, physiological changes relate to the physiological condition of a person and includes factors like flexibility, inactivity, strength, endurance, nutrition, sleeping habits, stress and general health (Christiansen, Baum & Bass, 2015). The SSPs described that they experienced limitations in their occupational performance due to a loss of endurance, strength, and hand function. Activities that they found challenging were mainly in their homes and communities.

Stroke survivor participants experienced challenges in homecare tasks inside the house such as cooking, washing dishes, washing laundry, cleaning, and caring for pets.

> "I find difficulty with the sweeping and washing of the dishes, that is why I don't do it anymore." [SSP 9]

> "I couldn't look after them anymore [the birds], so I had to sell them." [SSP 11]

Many SSPs reported needing assistance to conduct homecare tasks outside the house such as doing grocery shopping because they were unable to carry shopping bags and struggled to manage money when paying due to the loss of strength and movement in their hands.

> “But before, I actually went alone [shopping] …. It’s now after the stroke that I take [my grandchild] with…. He helps carry, ... it’s too much stuff, man .... the stuff is too heavy .... It’s the hand that is still not right, completely right ... to hold the bags [is difficult].” [SSP 10]

> “[What is most difficult is] to pay for it...and to take the change and put it back in my wallet .... I can only use my right hand to put my money away …. Can you see how long it take him [the hand] to open [opening left hand to demonstrate]?” [SSP 11]

Stroke survivor participants also found that unilateral weakness in the upper or lower limbs influenced their ability to engage as before in leisure activities like playing guitar and dancing.

> “Yes, I mostly sit and tinker at home …. Before the stroke I played much better guitar than now .... I struggle a bit with the chords …. When a chord starts with G, G and A, then I struggle to get to G major .... But it went easier before the stroke ... It’s the struggle with the fingers .... [They] don’t want to bend so well, man.” [SSP 10]

> “Look, I can’t [dance] now…like here at this wedding …. I’m not really a dancer, but I mean, I always shuffled around and stood and so on, now I can’t anymore. Now I need to sit the whole time.” [SSP 7]

Neuro-behavioural subsystem changes

Neuro-behavioural subsystem factors, according to the PEOP model, refers to how a person regulates their sensory and motor systems. This is used to perceive himself and his environment as well as to move through his surroundings through motor planning, motor control and postural control (Christiansen, Baum & Bass, 2015). Additional to the loss of strength and endurance reported as a physiological deficit, most of the participants reported changes in their occupational performance inside and outside home due to a loss of mobility. Stroke survivor participants experienced dependence on others to propel their wheelchairs, especially outside.

> “Outside is a problem, outside in my wheelchair. I [just] sit in my wheelchair then they push me.” [SSP 11]

Additionally, SSPs found that they could no longer walk independently, ride a bike, drive, or use public transport.

> “No look, now I have to go in a wheelchair. Other days I walked, walked myself, ran.” [SSP 1]

> “Because a bicycle I can’t ride anymore.” [SSP 6]

> “No, not at all. I don’t use the taxi now at all.” [SSP 10]

Subsequently, participants experienced becoming dependent on others for mobility outside their homes.

> “So, I avoid it [driving] rather and any far distance driving, I rather get someone to take me.” [SSP 3]

> “My wife and I must always find someone, like my son in-law was off for two days ... then he will take me to the hospital, dayhospital and so on.” [SSP 11]

Which decreased their ability to participate in activities outside their homes such as watching live sport outside.

> “I haven’t gone to [watch ruby] in a long time .... [I stopped going] because I cannot move this side.” [SSP 11]

Cognitive changes

Additional to the physical changes SSPs experienced an increased dependence on family and friends due to residual cognitive fallouts. In line with the PEOP model, cognition refers executive functions such organising thoughts, reasoning, making decisions, memory and attention which allows the achievement of a specific goal (Christiansen, Baum & Bass, 2015). It also includes the ability to communicate (Christiansen, Baum & Bass-Haugen, 2005).

Stroke survivors found that they required assistance to engage in occupations that required conversations such as shopping, going to the clinic, participating in religious activities like evangelising in the streets and going to church or participating during social gatherings.

> “My daughter always goes with me ... before I went alone. I still did before the last stroke ... I still went to the shops alone … [I don’t go alone now] because I don’t speak well.” [SSP 4]

Participants also were dependent on family members to assist them in remembering important things or to assist with everyday problem solving.

> "I still go regularly [to the shops], ma'am … but I take my grandchild with. He must go with me ... He must … check that I buy correctly .... But before, I actually went alone .... It's now after the stroke that I take him with yes." [SSP 10]

Spiritual changes

The PEOP model describes spirituality as providing the context to the way a person interprets situations to create meaning and significance (Christiansen, Baum & Bass, 2015). Additional to the physical challenges posed by their stroke, participants reported contrasting spiritual viewpoints to their disabilities. Some questioned their belief system and had feelings of disappointment in the spiritual support they received, while others found strength in it. Participant eight expressed deep disappointed and felt abandoned by God.

> "I'm disappointed … it feels to me as if the Lord has forsaken me. Do you understand?" [SSP 8]

Whereas SSP 7 was thankful for God's protection in the process of recovery.

> "It was a shock, really. I thought that night I'm going to die this way. Ooh, but okay, the Lord is good ... The Lord's hand is on me ... I can only say thank you to the Lord every day, every night when I go lie … I pray every night. I say thank you to the Lord." [SSP 7]

Psychological changes

The last of the personal factors where SSPs experienced changes was in the psychological domain. The PEOP model defines psychological factors as core emotions and feelings that a person experiences which influence their performance (Christiansen, Baum & Bass, 2015). This includes factors such as motivation, self-concept, self-awareness, self-esteem, and a sense of identity (Christiansen, Baum & Bass, 2015). During the interviews with SSPs, three different psychological changes emerged from the data.

Firstly, SSPs reported feelings of frustration, bitterness, disappointment, and shame. These feelings emerged from their inability to complete tasks independently and dependence on

others for help, being unable to help others as well as the loss of independent home and community mobility.

> “I want to wash myself ... Yes look, she washes me, my wife, all these things she washes for me. Uh, its bitter for me. This is a terrible disease, ma’am.” [SSP 1]

> “All I can say is, I’m bloody sorry that it happened …. I could have done so much, you know, and now at the age of sixty-three, to sit like this and struggle with this, a leg, and an arm .... I could have still caught sheep, man ..., driven a tractor and ... such things.” [SSP 8]

> “I feel very frustrated by [the effects of my stroke]. Just because I can’t move, I can’t walk. It makes me very angry [participant started crying].” [SSP 11]

Secondly, SSPs also reported difficulty in accepting the loss of function and worrying about future. They found it difficult to accept themselves with their changed bodies and missed being able to do tasks independently.

> “I miss those things a lot. Because I could stand up, could stand on my two feet. I could wash myself, could do everything alone. Now I can’t do it anymore.” [SSP 11]

> “The family was fine [with me after the stroke] it was me only who was not well …. I saw myself [as] disabled …. It was difficult for me …, I couldn’t accept myself …. It was difficult for me on my side when I got the stroke, I couldn’t accept it.” [SSP 12]

Stroke survivor participants also experienced concerns regarding the loss of finances, how to pay off debt and how they would survive socio-economically in future.

> “It actually breaks me down. For example, I bought the house .... Now I would like to finish paying the house’s debt because the man and woman of the house have died. So, they sold me the house with debt. And now it is quite uncomfortable, actually I can’t take my SASSA money and pay the debt to get the house on my name.” [SSP 11]

> “Emotionally…. the future bothers me unfortunately … I have to be honest because at the moment, you know … I think COVID has also highlighted a lot of things for a person, you know, concern [about] people’s financial circumstances and things. I am struggling now. I only got my money from SASSA again for the first time this month. It was a hell

of a struggle to come right with them ... my mother, she is almost 89 now and financially … I cannot completely rely on my family [like this].” [SSP 3]

Thirdly, SSPs expressed a resignation to fate and reported feeling that they could not change things such as the loss of social interaction.

“Oh, gosh, I [just] have to accept it [referring to the loss of function and independence], my dear.” [SSP 7]

“No,no, I don’t want to participate in [social events] ... I’m just in people’s way, man “ [SSP 10]

4.3.1.2 Changes due to environmental factors

In addition to intrinsic personal factors, extrinsic environmental factors emerged that influenced SSPs ability to engage in their occupations which effected their transition back to the community. The PEOP model proposes that participation is influenced by the characteristics of the environment in which the person lives and engages in daily activities, including factors such as culture, social determinants, social support and social capital, education and policies, the physical and natural environment as well as assistive technology (Christiansen, Baum & Bass, 2015). From the above mentioned five sub-categories, several codes emerged as presented in Table 4.9.

Table 4.9 Environmental factor changes

THEME 1	CATEGORIES	SUB-CATEGORIES	CODES
Changes experienced in occupational performance	Changes due to Environmental Factors	Social Support	Decreased social involvement of family and friends
			Positive of support given by family and community
		Social and Economic Policies	Dependence on others for community mobility
		Cultural Values and Beliefs	Changes in attitudes from community and family
		Physical and Natural Environment	Inaccessible structural layouts in homes & community restricting mobility, homecare, selfcare and leisure
			Inaccessible natural environment restricting home and community mobility

Social support

Stroke survivor participants reported two contrasting experiences in terms of the social support they received after their stroke and how this influenced their participation in occupations. The PEOP model defines social support as part of social support and social capital. This refers to the relationships, networks and group affiliations that provide social, practical or instrumental

support (Christiansen, Baum & Bass, 2015). Some SSPs experienced a decrease social involvement of family and friends whereas other participants were positive about the support given by their families and communities.

Only a few SSPs reported decreased involvement of family and friends. Stroke survivor participant 4 for example found that family no longer visited her while SSP 8 expressed concerns about his care in the future as he did not believe his children would assist him.

> "Since I am at home [after the stroke], family do not come anymore." [SSP 4]

> "Going forward I want to know, who is going to help her [wife] to help me? ... Because this woman will not be able to [care for me] for the rest of my life ... help me dress ... and help to wash and dry and such things .... That worries me ... you know because … a person's children, they say that they will take care of you, but ... listen to the elderly ... complaining on the radio .... They will straight up say, 'no dad and mom huh-uh hold it', you know ... I know that will happen." [SSP 8]

In contrast, most SSPs experienced the social support received from family, friends, and the community as a positive experience.

> "The support of my family ... was very good, and still is and that's why I at least move a bit .... And through that I at least move a bit to my old friends and so. But they helped me to help the young people again …. [They supported me by telling] me you can go there and asked me 'are you okay' and tried to do everything that [I] wanted." [SSP 9]

> "The church also helped, yes helped a lot .... They prayed a lot .... Prayed and came in, came to visit." [SSP 10]

Social and economic systems and policies

Additional to a person's social environment, the local policies and legislation dictate the availability and access to resources in the society (Christiansen, Baum & Bass, 2015). One of the main experiences SSPs reported was dependence on others for community mobility, often due to the lack of disability friendly, accessible public transport. Participants experienced a loss of independence while engaging in activities outside their home such as going to the clinic or shops, traveling out of town, attend social events and driving.

> “I don’t go out anymore ... I mean, I walk, myself, to my neighbour across [the street] .... But further I don’t go anywhere. Unless my sister or someone comes to get me. Then I go to her now.” [SSP 4]

> “I have problems to get in the taxi … I have to hold on when get in now … There must be someone to hold me.” [SSP 12]

> “No, how can I say [it], I struggle with getting … in the taxi. Look, the taxi is a bit high, the step right … now, our taxi that comes to fetch us [to go to the stroke group], it has a small step that … we step on and get in …. But these [normal public] taxis here don’t have those things.” [SSP 7]

Cultural values and beliefs

The cultural environment of a person is characterised by beliefs, traditions, ceremonies and the use of time which can influence a person’s occupational performance (Christiansen, Baum & Bass, 2015). Only one participant perceived changes in attitudes from family or community members, which mainly influenced their social participation.

> “Many, many of them have changed in their attitude towards me …. Like before, before the stroke we communicated a lot … but now then don’t even speak to me … my friends …. [I experience their attitudes towards me] are negative.” [SSP 9]

Physical and natural environment

Additionally, environmental factors that often influence participation in occupations are the physical and natural properties of the environment (Christiansen, Baum & Bass, 2015). The physical environment refers to how accessible and usable the built and the natural environment is. The natural environment includes factors such as the terrain, geography, air and climate (Christiansen, Baum & Bass, 2015). Stroke survivor participants experienced that inaccessible structural layout in homes and community restricted their mobility, homecare, selfcare and leisure.

> “I had an opportunity last year to swim at a place, I really love water... for some or other reason, the last step before you get out is always very high .... If I don’t get help or something, then it’s just difficult.” [SSP 3]

> “No, no, I haven’t been upstairs in a while [referring to the second floor] .... That’s why I have put the TV here downstairs, ma’am.” [SSP 1]

In addition to the structural challenges of the built environment, SSPs experienced that the inaccessible natural environments restricted their home and community mobility after their stroke. Participants experienced that uneven terrain and far distances made it challenging to move around independently which led to decreased participation in activities such as gardening and walking along the beach.

> “To go outside, I can’t walk there, man [referring to uneven terrain in the backyard].” [SSP 1]

> “Yes, look, ... look, in the summer here by us, even in the winter if it’s a nice day, to drive along the sea, and walk against the sea. But its not so easy now because of the soft sand and those things, I don’t even do it. I can walk on the walkway , but that’s not enough, I want to walk by the sea.” [SSP 3]

Additionally, SSPs experienced avoiding tasks, letting others go on their behalf or requiring the assistance of family members and friends because of natural environmental barriers.

> “No [I cannot manage my own finances], not at all …. You know, it’s [difficult to access] to the bank …. I ask my sister to go … [because] the bank is far …. And now I need to get off [from the taxi] at the café and then go [to the bank] and its difficult for me.” [SSP 9]

4.3.1.3 Changes within occupational and performance factors

The last category that emerged from the data in theme one was specific changes in SSPs occupations and performance. Christiansen, Baum and Bass-Haugen (2005) in the PEOP model, explain occupations as the typical things people do daily, which includes their activities, tasks and roles. Occupational performance on the other hand refers to the doing of the activities, roles and task that are meaningful to the person through the intricate interactions between the person and environment (Christiansen, Baum & Bass, 2015). The categories and subcategories record the SSPs experienced of changes in their occupations as well as changes in their roles and are presented in Table 4.10.

Table 4.10 Changes within occupations and performance factors

THEME 1	CATEGORIES	SUB-CATEGORIES	CODES
Changes experienced in occupational performance	Changes within Occupational and Performance Factors	Changes in the structure of activities	Limited leisure participation
			Socialising being limited to the home
			Inability to generate an income and dependence on a social grant
			Need to adjust how tasks are completed
		Changes in roles	Loss of the role of breadwinner
			Loss of the role of helper/ carer/ and being an authority figure
			Reassignment of homecare role

Changes in the structure of activities

Christiansen, Baum and Bass (2015) in the PEOP model, explain that occupations are engaged in for a specific purpose which consist of social and temporal dimensions. For example, occupations can be engaged alone or with others, to fulfil specific roles or obligations or form part of one's identity. Additionally, occupations differ in time, sequencing, frequency, and duration. (Christiansen, Baum & Bass, 2015). During the semi-structured interviews, it emerged that participants identified changes in their ability to engage in two specific areas of occupation, namely leisure and income generating activities as well as temporal changes such as tasks taking longer than previously.

> "It's as if now, it's hard man. Not like, hard, but I would say it takes more time, I did it faster before the stroke [referring to gardening]." [SSP 10]

Firstly, participants experienced limited leisure participation and socialising being limited to the home. Participants experienced that they no longer could participate in previous leisure activities such as being part of a brigade, playing in a band, dancing, or playing or attending sport such as netball and rugby.

> "No, we [referring to the music band] have now completely broken up ... After I had the stroke, and now it is all broken up. The men have now split up, man." [SSP 10]

> "No, I don't play it [netball] anymore." [SSP 9]

While this was the view of the SSPs, OTP 1's lived experience was that stroke survivors due to them often being older, often engaged in limited leisure activities even prior to their stroke. She therefore believed this previous lack of engagement exacerbated their engaging in limited leisure activities following their strokes.

> "… But in terms of actual leisure activities like sporting activities, I have never come across patients that have actually said to me that they were able to return to doing something along those lines. And it's usually an older population. So, [when I think about the characteristics] … of the patients- it's a lot of domestic workers, it's manual labourers. I don't often really explore the leisure participation or those kinds of occupations. It's never, how can I say on, on the forefront of my assessments or intervention. Because often there aren't many or any leisure activities that the patients were doing even pre-stroke .... So, I'd say I wouldn't think there's any, like community integration with regard to leisure exploration or cultural activities or things like that." [OTP 1]

The collective experience of SSPs was of becoming more homebound and only engaging socially if people come to visit at their homes.

> "I don't worry much about the community and going out. Because I am just here at home .... I just sit here outside and all day but otherwise it's all right." [SSP 9]

> "I no longer go out to [visit] people, and people hardly come to me." [SSP 4]

Additionally, participants experienced an inability to generate an income and therefore became dependent on a social grant.

> "It's hard for me now, I cannot work anymore. Yes, I was working every day in construction work, and I cannot work anymore. I just have to sit at the TV watching all the time." [SSP 6]

Lastly, SSPs found that they needed to adjust how tasks were completed. This included being more conscious to the loss of sensation when working with heat, asking family members to assist with aspects of meal preparations like peeling and cutting, also engaging in religious activities in different ways and completing tasks at different times of the day.

> "I sit here, like this, and do my prayers .... Then I'm finished .... Yes, I want to go down on my knees but I can't open my hand, this hand doesn't want to open." [SSP 6]

> "I do my shopping very early in the mornings … It's just so much easier, and it's quieter for me and it's easier for me to move, especially now, it's just so much easier, and then I get parking right in front so I can get out [of the shop], load the stuff and shoot out. I do

not have to reverse, and I avoid reversing as far as possible .... And fewer people. It's a twofold thing for me." [SSP 3]

Changes in roles

Christiansen, Baum and Bass-Haugen (2005) further highlights that roles include the need to complete specific activities within these roles which define peoples positions in the family and society. With the inability to engage in activities to generate income SSPs experienced the loss of the role of breadwinner.

> "So, I would be able to go back to work, because I have to. I'm a single mom who has to take care of my child and my grandma and grandpa are pensioners … It's essential [for me] to go back to work. It was actually … [the] main thing I wanted to do. But I still do not work, so it was actually the thing that upset me the most, that I could not go back to work." [SSP 2]

In addition, SSPs also experienced the loss of the role of helper/ carer and being an authority figure.

> "I was happy when I was with my children .... We were helping each other; I would prepare for them when going to school; I would wake up and was able to prepare for them …. [But now my happiness] is a little now … because I cannot take care of them myself … because I cannot help them." [SSP 12]

> "I am, what did I want to say. I liked doing maths with my children, but I can't anymore, I can't remember that well .... Maybe with the questions, I am very good at maths, very good, but sometimes, it takes me long to answer them .... But then he, [my grandson], asks 'Why ma take so long?' Then I tell them 'I need to think for a bit''. [SSP 4]

Lastly, due to being unable to engage in certain activities, roles were reassigned such as the reassignment of the homecare role to other family members. This included no longer managing finances, doing shopping, cooking, or cleaning.

> "I do not work with the finances anymore, because the one who works now [is my wife]. She is now more in control ... I keep the money ... but if she wants something then …she asks then I must now [give] it to her, if she wants to buy something or so… [It was not like this before], I always did everything, before the stroke." [SSP 7]

4.3.2 Theme 2: Perceived and experienced barriers to community reintegration

The second theme that emerged was the barriers to community reintegration that the SSPs perceived and experienced after their stroke. Table 4.11 details the categories and subcategories that emerged from data through inductive reasoning using the PEOP model lens.

Table 4.11 Theme 2 Perceived and experienced barriers to community reintegration

THEME 2	CATEGORIES	SUB-CATEGORIES
Perceived and experienced barriers to community reintegration	Personal Factors	Physiological Barriers
		Neuro-behavioural Subsystem Barriers
		Cognitive Barriers
		Psychological Barriers
	Environmental Factors	Social Support Barriers
		Social and Economic Systems and Policy Barriers
		Cultural Barriers
		Physical and Natural Environmental Barriers
		Assistive Technological Barriers
	Occupational & Performance Factors	Tasks

As with the first theme, three categories emerged for the second theme: personal factors, environmental factors and occupational and performance factors that presented as barriers to community reintegration.

4.3.2.1 Personal factors presenting as barriers

In accordance with the PEOP model, the findings that emerged were divided into four sub-categories representing the personal factors that SSPs perceived and experienced as barriers to their occupational performance and reintegration into their communities. Table 4.12 presents the subcategories and codes that emerged from the interviews.

Table 4.12 Personal factors perceived and experienced as barriers

THEME 2	CATEGORIES	SUB-CATEGORIES	CODES
Barriers to community integration	Personal Factor Barriers	Physiological Barriers	Loss of physical strength and endurance
		Neuro-behavioural Subsystem Barriers	Loss of mobility and visual impairments
		Cognitive Barriers	Memory loss and forgetfulness
			Speech impairments
		Psychological Barriers	Uncertainty about abilities and fear of falling
			Loss of motivation

Physiological barriers

The physiological barriers to community reintegration as perceived by SSPs after their stroke was the loss of physical strength and endurance. Specific reasons for changes in their

occupational performance were reported as being too weak, being unable to stand for long periods, getting tired quickly, not being able to use their hands or having a weak grasp due to unilateral weakness or paralysis.

> “No, not at all [referring to cooking] .... I cannot stand for long ..., I get tired, and I can also not use my [both] hands.” [SSP 9]

> “[when washing dishes] You have to hold the dish with another hand, it is difficult now [to wash dishes] because with which hand am I going to hold it because I don’t have it.” [SSP 12]

Physiological factors specifically affected mobility in two ways. A weak grasp and unilateral paralysis influenced their ability to independently propel their wheelchairs especially outdoors.

> “Outside is a problem, outside in my wheelchair …. [I cannot move the wheelchair alone because] I can only use the one hand. I cannot move in the wheelchair with the one hand.” [SSP 11]

Secondly, SSPs found the loss of strength influenced their independent gait as well as their ability to access public transport due to the high step into a taxi.

> “Look with the stroke I hurt my ankle as well and that is still … a bit painful when I stand too much or when I walk too much … I can’t do what I use to do .... I liked walking, walking far and so, or jogging or maybe more, but that is the only thing.” [SSP 2]

> “… how can I say, I struggle with getting … in the taxi. Look, the taxi is a bit high, the step ….” [SSP 7]

The loss of endurance and hand function also affected several SSPs ability to return to work as they were unable to stand for prolonged periods or lift heavy items.

> “Personally, I would be willing to go stand inside a shop again, but I cannot stand for long.” [SSP 3]

> “I do not have two hands …. I only have one hand ... at work, with one hand I must work. Must pick up bricks and throw the cement and put it down, right. That's all that makes it difficult for me. Furthermore, I am all right.” [SSP 6]

The last physiological factor identified by SSPs that acted as a barrier to occupational performance was having recurrent strokes after having received rehabilitation.

> "When they sent me home, I started practicing here at home. Going out by the door, with my cane, I walked from one corner to the other. But when I got the second stroke ... Then I slammed down ... I cannot walk outside, I cannot. I'm just in the wheelchair …." [SSP 11]

Occupational therapy participants agreed and also identified that the severity of the stroke and the age of stroke survivor was a barrier to community reintegration.

> "I think also it's dependent on age .... So, the older people, [those with] multiple strokes, obviously their community integration is very poor. And a lot of the times they become bedridden and forgotten in the community." [OTP 1]

Neuro-behavioural subsystem barriers

The main perceived neuro-behaviour barrier to community reintegration was the loss of mobility. In addition to the physiological factors that affected mobility, participants found that neurobehavioral factors such as poor balance, control of movement, residual epilepsy, and visual deficits also played a role.

> "It's harder [referring to family gatherings] .... Because I'm struggling ... with movement and so on ... I stuggle to walk from the one family [member] to the other " [SSP 9]

> "…because now I also get epeileptic fits." [SSP 8]

> "My driving is not good, because of my eye …. Because you see ... even if you look left and right … because your vision jumps, I have no idea how far that car is, or sometimes, I don't even know if there is a car, it jumps so bad. So, I avoid it rather and any far distance driving, I rather get someone to take me." [SSP 3]

The lack of community reintegration due to poor mobility skills was confirmed by the OTPs.

> "With[in] the … township context, getting around in a wheelchair [is a problem because] often the stroke people are not self-propelling. They often need people … to push them in the community. So, I don't think they're necessarily that independent, that integrated into the community in that aspect." [OPT 1]

> “Yes, so … basically going to the toilet, getting dressed and also coming to the clinic [is a challenge] …. Lots of [stroke survivors] are in wheelchairs, so they ask the family to assist them with transportation to the clinic. And once they’re at the clinic, then they often need assistance [with] going fetching their file [and] going to see whichever health professional they are coming to see.” [OPT 2]

Cognitive barriers

In addition to the physical factors, SSPs reported that cognitive factors such as memory loss presented as barrier to managing their healthcare independently, such as remembering clinic appointment dates and to take their pills. Additionally, SSPs reported increased dependence on others to remind them where they put their belongings or practical aspects in the home such as closing taps.

> “I struggle with it because I do not write well either, is very difficult for me, sometimes I forget about things. For example, when I need to go to the clinic, I forget my dates or sometimes I forget to drink my pills.” [SSP 9]

> “I forget … [like when] opening that tap and washing myself. [When I then] come to sit here, [I] see that the tap is still running inside there.” [SSP 6]

Stroke survivor participants also reported that, speech impairments influence their ability to reintegrate into their communities and influence their ability to engage in social events, attend health appointments alone and do homecare tasks such as shopping.

> “I do not go out anymore ... [because] I don’t speak well ...” [SSP 4]

Occupational therapy participants confirmed that cognitive factors were one of the most prominent barriers to community reintegration of stroke survivors.

> “… cognitive fallout is an issue … [and] the lack of the ability to communicate obviously affects community integration as well. Because those are the patients that can't make their needs known. I'm just picturing maybe someone with a stroke trying to go to the local shop on the corner just to explain, you know, what they need would be so difficult.” [OTP 1]

> “I think, besides the physical part … the patients with the multiple strokes, usually those are the ones with a cognitive fallout. Those are the ones … [who] are also unable to

speak maybe. Those are the ones that are being fed through PEGSs (fed per cutaneous endoscopic gastrostomy) or NGTs (Nasogastric Tubes). So, I'm thinking those are the patients that generally are kept indoors." [OTP 1]

Psychological barriers

Stroke survivor participants reported two main psychological factors that acted as barriers to reintegrating into their communities. Firstly, participants reported experiencing uncertainty about their abilities and a fear of falling, therefore avoiding activities in the home such as getting in and out of a bath or shower, walking downstairs or going to church.

"Now, they gave me at … at Lentegeur, a plank [bath board] … that I should put on the bath, and then I should sit on it and wash myself …. I have not yet [used it] because I'm so afraid, man." [SSP 7]

"But adjusting in ... the community, I don't really ... go now to church at all .... I am scared I will fall in the church, because now I also get epeileptic fits." [SSP 8]

Secondly participants reported a loss of motivation. This decreased their drive to attempt completing tasks alone, going outside the house and attending social events.

"I go up here sometimes. I also have to, just for, to get out of the house .... But I don't feel like it, becuse I don't have the courage, [it is so much]trouble to go out." [SSP 1]

"No after the stroke, and oh, I don't know why. I just am ... It's like my desire is gone." [SSP 8]

Similarly, OTPs reported that loss of motivation, confidence and a sense of helplessness was what they observed with stroke survivors. This they believed often influenced their drive to achieve independence in tasks.

"I think just the people with disabilities … often don't even have the confidence to go out … It's like the intrinsic [motivation]. Like, they personally don't actually want to integrate into the community ... they want to be left alone in home all the time." [OTP 1]

"a lot of them when they … [have achieved] the maximum function that they have, they go into a kind [of] ... a slight depression …. I had about two [patients] that missed appointments continuously. I eventually did a home visit. [The patient said] 'no, why must

I get up, I've got nothing to live for, my family has to take full care of me now.' So, they've lost like hope." [OTP 2]

4.3.2.2 Environmental factor presenting as barriers

In addition to personal factors that presented as barriers to community reintegration, participants also experienced and perceived several environmental factors as barriers. In line with the PEOP model, the codes were categorised according to the 5 sub-categories found under environmental factors as seen in table 4.13.'

Table 4.13 Environmental factors perceived and experienced as barriers

THEME 2	CATEGORIES	SUB-CATEGORIES	CODES
Barriers to community integration	Environmental Factors	Social Support Barriers	A lack of or excessive social support from family
		Social and Economic Systems and Policy Barriers	Inaccessible transport
			Poor medical policies surrounding the coordination of rehab and discharge services
			Poor policies regarding service users with mobility limitations
			Economic factor like the loss of finances
			COVID-19 pandemic restrictions
		Cultural Barriers	Cultural and personal values such as such as not wanting help and fearing the communities' attitude
		Physical and Natural Environmental Barriers	Built environmental factors like stairs and small spaces
			Natural environmental factors like uneven terrain and long travel distances
		Assistive Technological Barriers	Inappropriate devices/ problems with devices

Social support barriers

Stroke participants reported that a lack of or excessive social support from family was often a barrier to community reintegration. Some SSPs reported that their families did not allow them to attempt completing activities alone. A similar observation was made by OTP 1.

"Sometimes when I want to do something they scold, mommy, go sit, or so on …. I must then sit." [SSP 7]

"[It's] the mindset or the thinking of the family and the caregiver of the actual patient. I find that the patients with the severe strokes are … kept in the home [and] not really involved in community activities. Sometimes the family doesn't seem [to] value allowing the person to… be outside and interact with others. So, I think it's family also [that limits community reintegration] … they're sometimes the challenge." [OTP 1]

Other SSPs reported insufficient practical support from family such as pushing their wheelchairs to activities in the community, installing rails in the house or not assisting financially.

> “No ... I haven’t been in church forever …. [I stopped going] because they do not want to push me.... They do not want to push me up here...with the wheelchair.” [SSP 7]

> “I, myself always asked … ‘Son, help me man [to put in rails] … [even though] I cannot pay [for] you everything. Finish with the work.” [SSP 1]

> “She, xxx, is the only one who supports. But my other daughter works … but she does not give us … let us say money, her money …. At the end of the month [she] doesn’t give her money.” [SSP 4]

Correspondingly, OTPs also confirmed the SPPs experience of the lack of or inappropriate social support from family, which influenced participants ability to attend appointments, be compliant with therapy or participate in activities at home.

> “... and obviously support. Because the most support that they get is mainly at our facility and not so much from their family. So, what we often try is to also have sessions with family members to obviously assist the patient … but you know, it goes to the one ear, exits the other ear and the patient is then back to where they were in the beginning with nobody to assist [them in] their … home environment [and] outdoor environment.” [OTP 2]

> “With the support … quite often we find that the support is sometimes [from] a minor … Like it's the patient's child that is the only one caring for them ... That’s definitely a challenge because it's often someone that’s maybe school-going. Or if it's someone older they can't really work to support [their families anymore] because they're trying to take care of this family member [who had the stroke].” [OTP 1]

In addition to the lack of social support from families, OTP 1 also reported that the wider social environment often influenced stroke survivors’ mobility in the community due to the unsafe social environments in the community.

> “Obviously [the family] worry about safety as well. Allowing someone in a wheelchair or on crutches or a walking frame, someone that’s mobility is affected, allowing them to be independent in the community. Like walking around, going on their own to the shop.

> Going on their own to visit a friend. I think that is also a big challenge …. They obviously worry about person's safety. You know, getting robbed, getting attacked, falling on the way to wherever they're going. So that's also a challenge, the safety of the actual community that they've been reintegrated into." [OTP 1]

Social and economic systems barriers

In addition to the lack of family support, SSPs experienced several social and economic system and policy barriers in their communities. One of the prominent barriers experienced by SSPs after their stroke was inaccessible transport. Stroke survivor participants reported avoiding using public transport due to the vehicle being not disability friendly. They also reported that taxi drivers were often in a hurry and rude.

> "I walk slowly, and usually struggle to get into a taxi so that's why I don't make use of [pulic transport] .... [It is difficult] to get into the door where I sit, it is like difficult for me, and many of the taxi drivers are rude with how disabled I am .... [They are rude] because, they hurry you along ... that is why I don't make use of [public transport] at all." [SSP 9]

Poor accessible transport and dependence on others for community mobility was confirmed as a barrier to community reintegration for stroke survivors by the OTPs.

> "I don't think there's much … in place for someone that has limited mobility. I know a lot of our patients, if they're going somewhere, they usually hire a car. They do the Uber, or they ask a neighbour to drive them. Because, obviously, like getting in a taxi, getting to the taxi rank and you have a mobility device is not easy … [Also] sometimes [the taxi drivers] charge more because you have something that's going to take up space. You know what I mean, like if you're carrying a frame or you have a chair that also needs to get into the taxi … So, I definitely think [the] actual transport in the community [is a challenge]." [OTP 1]

Stroke survivor participants also experienced poor discharge policies and referral pathways for rehabilitation and limited rehabilitations services at their local clinic as a barrier to their continued rehabilitation following discharge and thus community reintegration.

Firstly, SSPs reported not being referred to clinic for further rehabilitation and rehabilitation staff not being available to book follow-up appointments.

> “Nothing yet. [Follow-up therapy] has not been available there yet … at the clinic. They do not have therapy yet …. That time when I got there [I saw] … no, the therapy is not there. Again, and again when I get there. But I see there are people there that give therapy now. But is remains like that at the clinic ‘the people of the therapy are not there’.” [SSP 6]

Similarly, OTPs participants confirmed that poorly organised clinic follow-ups and the long waiting times were a barrier to stroke survivors’ attendance of therapy and negatively influence their functional recovery after their stroke. Occupational Therapy Participant 2 perceived that the long waiting times were often a consequence of reception staff prioritised the patients waiting for doctor appointments and not necessarily those waiting for their therapy appointments.

> “Another barrier is … if a patient is coming to the doctor their file is given ASAP. [On the other hand] if a patient is coming to a therapist, they’re waiting long …. I feel that that’s my biggest barrier in providing my services, because my patients come to me [saying] ‘I’ve been waiting an hour, I’m exhausted, I must still go to the physio.’ So then [the] session [is] rushed because [the] patient wants to now go home, or [the] patient needs to go and empty their [catheter] bag or they’re hungry.” [OTP 2]

> “I know had about two [stroke] patients, in a mothers’ group that met every Wednesday they [struggled with] getting to their meetings and also days clashing with the physio appointment, OT appointments, doctor’s appointments.” [OPT 2]

Secondly, SSPs experienced that insufficient information was provided on accessing further services in the community after discharge. In agreement, OTPs highlighted that the lack of clear guidelines regarding how to access services, limited patients’ ability to benefit from resources such as social grants.

> “I don’t want to be helped sooner but … if the information was correct in the beginning, then one would not have such problems. At the end of the day one of their workers came out to come get something in her car, [I] asked her a simple question, she helped me nicely …. [After this lady helped us] we climbed in the car, drove here, and they gave me a date to see the SASSA-doctor and for when I must come back, as easy as that, and that’s it.” [SSP 3]

> “A lot of people do not know about the disability grant and how to apply and, yes, get access to getting a disability grant …. The disability grant is not like an open book to the community .... They have to speak to somebody or hear from neighbours or friends or something about the disability grant and then enquire at the clinic how it works.” [OTP 2]

Thirdly, some SSPs reported struggling to get to appointments for rehabilitation at the clinic.

> “Look, they told me I should go to the clinic, to the day hospital … for the classes. They have classes or something like that, that they offer…for the physio. The reason [for not going] is that I did not have money every time to go to there …. That is actually the main, the main reason …. That is why I gave myself exercises here at home.” [SSP 2]

Lastly, of the SSPs that did receive follow-up rehabilitation some found that the therapy was not appropriate and felt that that it made no difference.

> “Oh those two weeks, three weeks .... I get there, we sit in a circle, then we chat and drink tea, eat cookies and stuff. Then they throw you a big ball. Now you can’t catch the ball. Then I just left that [refererring to the stroke support group his wife took him to].” [SSP 11]

Similar non-compliance with treatment was experienced by OTPs who experienced that poor buy-in and compliance with therapy was affecting the levels of communtiy reintegrations being achieved by stroke surivors.

> “So, in all honesty, their mobility can improve but compliance is the problem .... I think that the compliance of actually going home and continuing or reinforcing what we’ve been teaching them at the facility, that does not happen, and I think that’s what hinders the physical mobility more.” [OTP 2]

> “I mean also the attitude when you, give therapy and advice, t it’s like “no, my sister said I must do this, so I’ll rather listen to my sister than to the therapist.” So, that becomes very challenging for us .... I think they trust more in their family because, for example, the sister’s aunty, she had a stroke and she learned this exercise on Google, so, that works better.” [OTP 2]

In addition to challenges in accessing continued care, participants reported that poor policies regarding service users with mobility limitations also limited their ability to access services in

the community. This included a lack of prioritisation of persons with mobility challenges at the local SASSA offices.

> “Here its every month. Every time that you go, they have a different rule [referring to the systems at the clinic] … but you must wait for your turn …. And you … actually go on an appointment … but when you get there, then you just have to wait.” [SSP 7]

> “[Getting service at the] SASSA in Eerste River is a problem in the sense of you aren’t seen as disabled if you walk with a crutch or a cane.” [SSP 3]

> “… fact that there isn't access to a SASSA office in the community is a challenge.” [OPT 1]

In addition to poor policies, SSPs found that economic factors like the loss of finances also presented as a barrier to community reintegration. The loss of finances prevented SSPs from engaging in previous leisure activities and they reported struggling to cover basic living costs.

> “The reason for this is many things changed in the youth choir. There are many things, financially is the first point. They went out a lot and I couldn’t go with, because I didn’t work and so that is actually the only way, why I didn’t go back, because I wasn’t financially strong.” [SSP 2]

> “[Before the stroke] I did not need money because it’s, there was always money ... to live well from .... We could always pay for everything that we wanted to pay for, could always go out, me and my wife, now we can’t anymore .... [Its a] very big change ... very big.” [SSP 8]

Occupational therapy participant 2 had a similar experience with her stroke survivor patients.

> “So, I have a patient who was a manager at a restaurant and obviously earned a very good salary, had her own vehicle, [was] doing quite well financially, and then after her stroke, because she couldn’t obviously meet up to the standards of her work, they asked her to resign and gave her a resignation package type of thing. But obviously that money did not last, so, now she has a disability grant. She had to sell her car, … and sell things in her household just so that she could basically survive .... In her household it’s her two kids, and grandkids, the kids were unemployed, so she was basically the breadwinner.” [OTP 2]

Lastly, the COVID-pandemic restrictions which limited group gatherings influenced SSPs ability to participate in activities in their community that they engaged in prior to their strokes.

> "... and the church with this Corona we have now, we can't go to church very much, go to church with these things." [SSP 2]

> "It's closed now because of Covid now. Now I can't go. I will go there again to do work. To do work again in the community." [SSP 6]

Cultural barriers

Stroke survivor participants also reported that cultural and personal values such as not wanting help and fearing the communities' attitude were presented as a barrier to their community reintegration, mainly in the form of avoiding certain social activities or not being willing to request assistance.

> "If I ... go to Montagu now and braai with my friends ... I will stand to one side. I will not go sit there with them and chat in the bundle. Do you understand?...Because they will tease me and say look at how this guy looks, you know .... I don't want it that way .... Because when I walk I feel ... someone is looking at me, and when I look around I see that they are looking." [SSP 8]

> "[People's attitudes are] a little difficult for me. The children shout at me 'rock star', now …. They shout at me 'rock star' … 'Abby the rock star'…. Because I walk like this now … I rock …. It does bother me now and then …" [SSP 6]

On the other hand, some SSPs reported no longer engaging in activities as there was someone else in the family had been assigned to do it.

> "At the moment I'm not doing activities inside the house anymore. Because here is someone that can do it, I just make myself coffee and a sandwich and so on." [SSP 9]

This cultural expectation was confirmed by OTP 1 that found that participants did not engage in activities after their stroke due to the expectation that their family members should take care of them and take over their responsibilities.

> "So, I would say the older, the grandmas and the older men, obviously there isn't much participation from their side. And I think it's mainly like, I don't want to say a cultural thing,

but they obviously expect their kids to take care of them and not do much … [like] cooking and cleaning." [OTP 1]

Occupational therapy participants also reported the cultural stigmatisation of persons with cognitive impairments in the community. Consequently, survivors are often being hidden in their homes by family members.

> "In terms of culture … the rehab worker that I work with … tells me that if patients are confused, especially the stroke patients, and [if] they speak about things that don't make sense, the people in the community that live nearby often think the person is cursed or, you know, that whole traditional aspect. And so, those patients are kept indoors. Like, we've actually seen that a few times where those patients are hidden away because of the stigma around the confusion and the cognitive fallout." [OPT 1]

Physical and natural environmental barriers

Stroke survivor participants also reported that the physical and natural properties in their environment presented as a barrier to their community reintegration. The SSPs experienced that build environmental factors like stairs and small spaces often made independent mobility a challenge. Firstly, SSPs and OTPs identified stairs as a barrier to community mobility.

> "Stairs remain my problem. If there are no railing and stuff, then it can be very [challenging]." [SSP 3]

> "I would say space in the patient's home … For example ... they've got stairs to enter into their home because they're living in a flat and then it so happens that they are on the third floor. So … you must carry the patient and bring up the wheelchair. So, that is also like quite a barrier." [OTP 1]

Secondly, SSPs and OTP found that small spaces presented as a barrier.

> "The space is small…." [SSP 12]

> "I'm picturing like the layout of some of the houses. The passageways are … super narrow between houses …. So, I think that's definitely a challenge. Like, if you think about trying to get a walking frame or wheelchair or someone on crutches through those very narrow spaces between the homes. I think, that definitely affects if they're going to

leave the home or … go to the shop or go to church. Like just getting out of your actual home will definitely be a challenge" [OTP 1].

"… we actually find out that the wheelchairs cannot fit through the doors in their homes, or they have difficulty because the pavements are quite higher for some weird reason, so they have difficulty ... when they're leaving their house, [to get] off the sidewalk … A lot of times, we've noticed when giving walking frames, there's no way to use it in the house because there's no space to actually walk with a walking frame." [OTP 2]

Lastly, OTPs also identified inaccessible amenities in the home made it challenging to complete tasks in the home and poor structural planning of public spaces limited access to services in the community.

"… many of my stroke patients come from very low socio-economic status, so they end up basically making fires outdoors to cook their food. So obviously that's then taken away from them because [of] all the hazards around it and because it is the outdoors." [OTP 2]

"As well as … the basic ADL[s] … just bathing themselves. [Many of my patients] use the bucket bath method …. So now they need obviously the family members to come in, to assist them with their personal hygiene, grooming, etcetera." [OTP 2]

"… the way the clinic is laid out … the rehabilitation services, the trauma and the doctors, we're all on the first floor which is a big challenge for our patients that are on crutches, in wheelchairs, using walking frames. So, sometimes to access us it is an issue because we actually had this happen last week where our lift wasn't working. So … when that happens, the patients can't access us. And often we like cancel sessions if the lift isn't working. So, that is just a challenge, I think, like structure of the facility." [OTP 1]

Stroke survivor participants also identified natural environmental factors like uneven terrain and long travel distances as a challenge. These factors presented as a barrier to participants being able to engage in homecare tasks like gardening or access services in the community independently.

> “The vegetables, that is difficult. I cannot go there anymore .... I cannot go there and now. I can go until there if I have someone that holds me and then ... I go there, there, but I cannot bend that well or so.” [SSP 4]

> “Because I can’t get to the shops …. I mean, I cannot walk until there … and its … a bit far for me.” [SSP 7]

Additional to uneven terrain, OTPs confirmed environmental barriers such as poor drainage in the streets, the lack of ramps, insufficient sidewalk areas and too high curbs.

> “I would say flooding is the big issue in this community .... The roads are often flooded. So, that’s a big issue for community mobility. Lots of potholes, like poor quality of the roads. There [isn’t] … a lot of pavement space. So, a lot of the times the patients are actually in the road and in danger, because … they’re being pushed or [are] propelling themselves in a busy road …. I haven’t seen any ramps you know, like to access some of the shops in this road … even accessibility to the taxi rank [is a problem].” [OTP 1]

> “The way the roads are set out, the curves, the pavements, they obviously were not constructed with the intention that … someone with a disability is going to be living on this street .... So, the curbs are super high. I know that’s the challenge for a lot of the wheelchair bound patients .... Then also, … the terrain around the houses definitely would affect if someone … is going to be up and about in the community - the loose stones, the sand [and] all of those things.” [OTP 1]

Assistive technological barriers

Coupled with structural and natural challenges the tools or appliances available or needed for people to participate in activities can influence a person’s ability to engage in activities (Christiansen, Baum & Bass, 2015). During the interviews it emerged that SSPs experienced that inappropriately devices or problems with their devices affected their independent community mobility. Stroke survivor participants mainly found that they were unable to propel their wheelchairs using one hand, especially outdoor over uneven terrain and were therefore dependent on family or community members to push their wheelchairs outdoors. Stroke survivor participant 6 additionally found that the wheelchair was too slow for him and desired a motorised chair that would allow him to move around in the community at a faster speed.

> "What I find difficult man, I want to go there, man. I want to go to that place, alone. But someone has to go with me, one of my children, you know, to walk with me. I would like to get to a place fast. I don't like waiting that long to use the wheelchair that I can only use one hand to pedal, you know. The button [referring to motorised wheelchair] would be easier for me because I can just sit and then go nicely...drive nicely. I can also pay for it; I don't have to get it for free. I could pay it off by them at the hospital. That is my greatest desire, man." [SSP 6]

Stroke participant 7 on the other hand was issued a walking frame but was unable to use it as she lived on the second floor and could not get down to the first floor alone.

> "I got that walking [frame] … at the club, the stroke club. I can't really use the thing because I don't really get to the bottom on the ground level." [SSP 7]

The OTPs confirmed they were often unable to issue appropriate devices to stroke survivors due to the lack of stock or not having the appropriate devices on tender.

> "Okay I think from the clinic side … the biggest challenge maybe is that … we don't have stock of the appropriate device for the patient. Be it a wheelchair or a walking frame. So, I think that obviously will affect aspects of community integration if they can't actually get around." [OTP 1]

> "Like the bath boards work fine, uhm, but the bath chair we actually noticed cannot actually fit in their bath because the bath is a bit small, it's too small .... Most of them don't have adjustability." [OTP 2]

> "One of the barriers that I have … is the limited assisted devices ... we don't have a wide variety and often many of these devices are not on tender." [OTP 2]

4.3.2.3 Occupational and performance factors presenting as barriers

The last category that emerged from the data was that SSPs experienced three main barriers to occupational performance due to specific characteristics of various tasks. Two sub-categories were identified as presented in table 4.14

Table 4.14 Occupational and performance factors experienced and perceived as barriers

THEME 2	CATEGORIES	SUB-CATEGORIES
Occupational & Performance Factors	Tasks	Heavy weights
		Tight clothing

Firstly, heavy weights made it difficult to complete tasks independent such as carrying shopping, returning to work which had elements of lifting weights in the job description.

> "I hurt my back with the stroke, and yes, I am back at my old job now, but … the lady[boss] said she first wanted to see if I'm strong enough to deal with the patient, so heavy weights are still a bit ... of a problem for me. That's the only thing I'm struggling with ... to be able to pick up a heavy patient or something." [SSP 2]

Secondly, tight clothing made it difficult to manage dressing activities independently.

> "... these tracksuit pant's legs, are narrow at the bottom, then I get it...over the ankle with difficulty." [SSP 8]

4.3.3 Theme 3: Perceived and experienced facilitators to community reintegration

The last theme that emerged was the facilitators to community reintegration that SSPs had perceived and experienced on returning home after their stroke. Table 4.15 details the categories and subcategories that emerged from the inductive reasoning using the PEOP model as a lens to conceptualise the participants experienced and perceptions on community reintegration after their stroke.

Table 4.15 Theme 3 Perceived and experienced facilitators to community reintegration

THEME 3	CATEGORIES	SUB-CATEGORIES
Perceived and experienced facilitators to community reintegration	Personal factors	Neuro-behavioural Subsystem Facilitators
		Psychological Facilitators
		Spirituality
	Environmental Factors Occupational & Performance Factors	Social Support Facilitators
		Social and Economic Systems and Policy Facilitators
		Cultural Facilitators
		Physical and Natural Environmental Barriers
		Assistive Technological Facilitators

Two categories emerged for the third and final theme: facilitating personal factors and facilitating environmental factors that facilitated community reintegration. In theme three no category emerged for occupational and performance factors.

4.3.3.1 Personal factor presenting as facilitators

In accordance with the PEOP model, the findings that emerged were divided into three subcategories and five codes representing the internal human systems that played a facilitating

role in occupational performance and reintegrating into their communities as can be seen in Table 4.16.

Table 4.16 Personal factors perceived and experienced as facilitators

THEME 3	CATEGORIES	SUB-CATEGORIES	CODES
Facilitators to community integration	Personal factors	Neuro-behavioural Subsystem Facilitators	Having attended in-patient rehabilitation
			Having had a mild stroke and a fast improvement in gait
			Independent mobility
		Psychological Facilitators	Physiological factors like motivation and drive
		Spirituality	Belief System

Neuro-behavioural subsystem facilitators

Most SSPs experienced having attended in-patient rehabilitation as a facilitating factor in their ability to reintegrate into their communities. This included the exercises they received, that support from the staff at WCRC and the home programmes they were given on discharge.

> "There they taught me at Lentegeur [in-patient rehabilitation centre] how to get in [to a taxi] .... All those things I learned there by the therapy place. To climb in and steps and so ... I don't struggle [to get into a taxi]." [SSP 6]

> "I learned a lot [at the in-patient rehabilitation centre] ...[I] excersided a lot in the morning from about 10 o'clock, every day… It helped a lot; I have to say .... I quickly made changes after the stroke .... Ma'am won't believe me, when I got there, I could not walk ... And when I left there, I walked." [SSP 10]

Occupational therapy participants confirmed that their some stroke survivors that had attended in-patient rehabilitation and who are younger reintegrated into their communities with greater ease.

> "Where our younger patients, uhm, who've gone through the rehab process and come to us fairly mobile and things like that, some of them are actually able to return to work." [OTP 1]

Stroke survivor participants also experienced that having had a mild stroke and fast improvements in gait was a facilitator to occupational performance after their stroke.

> “Look, my stroke was not, I would say not a big, it wasn’t, I could still talk, it was actually a benefit I could still talk, I could still say what I want … [and] like in Tygerberg Hospital, I started giving myself physio, right there in bed I started.” [SSP 2]

> “I'm thankful I didn’t 't get such [a] serious [injury]… because I got to a point where I could walk so fast so quickly.” [SSP 3]

One of the reasons why having attended rehabilitation, having had a milder stroke and a fast return of gait was a facilitator to community reintegration was the consequent increase of independent mobility as reported by both SSPs and OTPs. Independent functional mobility, driving and using public transport facilitated community reintegration.

> “I go, I take a taxi [to go to the clinic]. Struggle, struggle, but I climb up there and, it’s getting a little better every day. It’s getting better every day, yes.” [SSP 2]

> “The thing that helped me, I guess that made me better now, [was when] I saw [I was] walking around the yard. [I realised] hey, I [can] get up and walk around the yard.” [SSP 12]

> “Where our younger patients who've gone through the rehab process and come to us … fairly mobile and things like that, some of them are actually able to return to work.” [OTP 1]

Psychological facilitators

Stroke survivor participants experienced physiological factors like *motivation and drive* a facilitating factor to community reintegration. This especially assisted SSPs to benefit from their in-patient rehabilitation that facilitated activity participation when returning home.

> “… At the rehab I … told them … ‘When I get out, I’m going to walk out of there.’ And I did walk without a wheelchair …. I had a walking pole, they gave it to me to bring home, to bring. So, it was after that, it was, I probably used if for two of three days, then I told myself I’m not going to walk with that thing. Then I just left if for a while and then I walked around in the house by myself.” [SSP 2]

> "… at Lentegeur [the in-patient rehabilitation centre] they knew my like that. I'm not someone who goes to sit … I try to do a thing … That's how I am … I don't sit there, not me." [SSP 4]

In agreement, OTPs perceived that motivation played a strong role in stroke survivors' compliance in continuing with therapy and continued functional recovery.

> "Okay, so I would say for some of my patients ... some of my patients are quite eager … quite far as it goes to, to recover. So, I would say they're strong-willed or their willingness to become clients ... I would say like their motivation." [OTP 2]

> "… some [stroke survivors] go into a depression and some accept what their condition is, still remain motivated to exercise, motivated to go out there, to join the support group, to go to the local shop, even though there are the external barriers." [OTP 2]

Spirituality

Lastly, SSPs viewed their *belief system* as a source of encouragement in getting stronger as well as when they feel uncertain about the future.

> "I prayed that the Lord would help me so that I can get stronger. Prayer always carries power." [SSP 2]

> "… but it's in terms of the future [that I worry about finances], but I am a believer too, you know …. He [the Lord] has always taken care of me to this point …." [SSP 3]

Occupational therapy participant 1 also found the stroke participant's belief system played an important role in who they were.

> "Because obviously, their faith is probably a big role or big part of, you know, who they are." [OTP 1]

4.3.3.2 Environmental factor presenting as facilitators

In addition to personal factors that presented as facilitators to community reintegration, participants also experienced and perceived several environmental factors as facilitators. In line with the PEOP model, the codes were categorised according to the 5 sub-categories found under environmental factors as seen in table 4.17.

Table 4.17 Environmental factors perceived and experienced as facilitators

THEME 3	CATEGORIES	SUB-CATEGORIES	CODES
Facilitators to community integration	Environmental Factors	Social Support Facilitators	Decreased social support
			Social support from the family and community
		Social and Economic Systems and Policy Facilitators	Accessible or alternative public transport
			Social welfare systems and policies
			External motivators such as dependants
			Supportive policies and systems e.g., medical systems, stroke support groups
		Cultural Facilitators	Cultural expectations of role fulfilment
		Physical and Natural Environmental Facilitators	External structures to hold on to
			Less crowded areas and even surfaces
		Assistive Technological Facilitators	The availability of assistive devices

Social support facilitators

Firstly, SSPs viewed the social support from family and their community as being a facilitator to community reintegration. Some SSPs reported *decreased social support* from family forcing them to attempt participating in homecare tasks independently.

> "Because in the beginning, when I came home, she did everything. She dressed me, everything. Later on, she saw no, this woman is very lazy … She said 'Come, mommy, dress like that … I'm not going to do everything for mommy.' And I struggle-struggled, but now I'm fine." [SSP 7]

On the other hand, SSPs viewed the social support from their family and community as a facilitator. Participants reported their church as a major source of support by encouraging and providing physical support.

> "… the church people were the people that also supported me…When I had the stroke…the church also motivated me a lot … Really, the pastor, the church council, all that." [SSP 2]

> "… They [the church] really carried me through …. Oh, they, they often came to me. They still come to visit me like this and bring me things, like bread and [other] things they bring me." [SSP 7]

Occupational therapy participant 1 confirmed that the church often provided an important social supportive network for stroke survivors.

> "I definitely think the church is a supportive network because, you know, [for] many of the patients that is their outing for the week. That is their social interaction. So, I think that's definitely a supportive environment…." [OTP 2]

Additionally, both SSPs and OTPs regarded neighbours, friends, and family as a facilitator to community reintegration by providing encouragement and physical assistance.

> "… my grandmother and grandfather also always motivated me to work harder to do something. I have to, they always pushed me, I have to be able to do that thing." [SSP 2]

> "[The] community helps me a lot, man. Last week Saturday after Ramadan another guy came to me and said "Sir, what do you need?'… They know me, the community knows me. They know, they know me well the community. They are very caring about me." [SSP 6]

> "Look, not all of them lack support, so a lot of them their husbands or their other family members come and assist. I've got a few where their children have left their jobs to look after their parents or parent, to look after them, to assist them at home because obviously there's the point where … [the person and his family realise] 'this is your highest level of functioning, you need full-time assistance…." [OTP 2].

Social and economic systems and policy facilitators

Stroke survivor participants also reported several social and economic systems in their communities that facilitated community reintegration. The availability of accessible or alternative public transport provided SSPs the opportunity to mobilise independently in the community, as also confirmed by OTPs.

> "… when I go to the stroke club … then a taxi [organised by the stroke club] comes to pick me up…now, the taxi of ours that comes for us, they at least have a small step that … that we step on and climb in…But the taxis here [in the community] don't have those things." [SSP 7]

> "For an example when I go to town to do whatever I am there to do, or I go to the bank, I use Uber." [SSP 12]

> “And I also think the reason why they attend the stroke group is also because they're fetched .... So, I don’t know always if they didn’t offer that [transport] service how good the attendance would be .... Like the ones that are, you know, not that high functioning.” [OTP 1]

Stroke survivor participants also found that the social welfare systems and policies such as disability grants, pension and community systems assisted with covering their expenses after their stroke.

> “Yes, the pension helps me actually.” [SSP 7]

> “Ma’am, to tell you the truth, My SASSA [disability grant] money, hey, it’s a little, but okay, it helps. It helps a bit for the things in the house and so on.” [SSP 11]

> “I join stokvels [a community savings system so that] I can save my money. Whatever I am thinking of doing I am able to do. But now I am assisted.” [SSP 12]

Other facilitating systems were supportive policies and systems such the systems in place to assist people with mobility limitations at the clinic.

> “No, the clinic is very good for me …. They handle me very well because they know me … When I come in …. I don’t still stand there, … I am disabled now, I walk right through and then I just sit there, wait for my counter to open. Covid checks, whatever, you know. Then I go.” [SSP 6]

> “Yes, but at our facility we see to all our wheelchair patients, the stroke patients, depending on your condition obviously and your functioning, we’ll see you first.” [OTP 2]

One of the most mentioned supportive systems was the availability of stroke support groups in the community. Stroke survivor participants and OTPs experienced this as a facilitator to regaining functional skills and having the opportunity to socialise.

> “[The stroke group] helped a lot … because [before] I just sat here and spoke to nobody but now, I can speak to them and so and I do [the] exercises that they give me and so.” [SSP 9]

> “The stroke club? Oh no, there its going very well …. We do exercises with our little hands and little feet … and legs, lots of little things that we do … it helps me a lot, really.” [SSP 7]

> “We have the Helderberg Stroke Support Group that supports us .... So, once the patient has seen, the OT at the clinic and I feel that they're kind of okay for discharge, I will discharge them to the Helderberg Stroke Support Group. I find has been a positive experience for most of them going there … because it's … a supportive environment they exercise, they do cognitive, and basic health screening there ... [The stroke group] kind of creates another community for them a community of other people that have strokes. So [community reintegration is] definitely facilitated … because it's also the social part and it's leaving the home and…being busy for that couple of hours for the day. And obviously building relationships, building friendships with people.” [OTP 1]

Additional systems in place that the OTPs experienced as a facilitator was the ability to conduct home visits, work as an MDT member and the assistance of midlevel healthcare providers like the CRW. Community Rehabilitation Workers assisted therapist in following-up on stroke survivors in their homes and informing the occupational therapist should any problems arise that need to be addressed by the therapist.

> “Okay … something that facilitated community integration is definitely the home visits. So, being able to see a patient in the home because then we get a better understanding … [of] the environment around the home … what they're able to access from where they are, like in the community…when we're able to see first-hand where the patient is going back to … It helps us just give a better advice to the patient…find out what's the appropriate mobility device, all of those things. So, I think, the home visits help.” [OTP 1]

> “I think, in terms of service delivery I can say that we offer a multi-disciplinary approach. Like … if we are visiting the patients in home ... it's never in isolation …. I think, the multi-disciplinary aspect also aids the patient in … offering them the best in terms of rehab services. So that they can be integrated into the community.” [OTP 1]

> “I think what also helps is we have the, the rehabilitation care workers .... They are usually the ones that are more active in the community [doing regular home visits] ….

> And then, they're obviously the ones that report back to us if there are any other issues or patients are not, you know, are not doing well." [OTP 1]

Additionally, OTPs perceived policies such as the community orientated primary care policy as well as the support of their managers allowed them to provide services that facilitated community reintegration with more ease.

> "I think the policy they're [currently] very big on, is Community Orientated Primary Care ... So, they basically want us to, move away from … the clinical setting and want us to treat the patients within their homes. So, they're very, uhm, big on that. They often criticise the rehab professionals at the clinic … that are working in the community but we're office-based or we're based at a facility …. The management always wants to know when we are integrating our Community Orientated Primary Care principles in our therapy if we're not going to the homes as often .... So, I think that's the one policy, like that's actually beneficial to the patient …. We need to basically make the healthcare and the services accessible to the patient… [by going] into the home. We come to them and not them coming to us. So, I think, that's something that facilitates community integration." [OTP 1]

Lastly SSPs also reported that having external motivators such as dependents provided motivation that assisted them in getting stronger and completing tasks independently.

> "… and my little daughter, because I fought for her, that was actually my main thing, I need to fight for my little daughter. I cannot sit in a wheelchair when I come home." [SSP 2]

Occupational therapy participant 2 further stated that as a therapist, providing external motivators also assisted stroke participants to comply wiht treatment.

> "I also think … as a therapist you can push the patient …. I would go to their houses on a random day and just see, okay, what are you doing…I think we push our patients to [say] 'hey, I need to work harder because the OT is going to come around at any time'." [OTP 2]

Cultural facilitators

Stroke survivor participant 6 also reported that the cultural expectations of role fulfilments served as a facilitator to activity participation.

> "Yes, my wife does nothing. I am the one that controls, money, everything. Shopping and such, I do everything myself, that's my job, according to my culture...." [SSP 6]

Physical and natural environmental facilitators

The main built environmental structure that SSPs reported as a facilitator to activity participation and community reintegration was the availability of external structures to hold on to. This allowed participants to mobilise independently.

> "I can walk, but I must hold against the wall .... To walk down the hallway ...."[SSP 4]

> "There has to be railings [when I walk up stairs]...the railings were not here [by these steps]...My son came to put them up, on both sides, for me." [SSP 8]

Occupational therapy participants also found that homes with access to basic amenities made it easier for stroke survivors to participate independently in their homes.

> "Some homes are more accessible, whereas some are limited. For example, some have toilets in their home, baths, shower, water in their home, and that's all-positive contributing factors to reintegrate into the community or into their environment." [OTP 2]

Lastly SSPs and OTPs found that less crowded areas and even surfaces make independently mobility in the community easier.

> "No, the only place that is easy for me to move in … Is at the church, where we hold the stroke club, I move easily there. … Because the space is bigger, and the support is there. … Because it's in a hall, and the chairs and stuff are out of your way." [SSP 9]

> "… For example, like simple things, like they've got driveways, so it's easier if they're in a wheelchair or using a walking aid, it's easier to get in and out of their home." [OTP 2]

Assistive technological facilitators

The last facilitating factor that the most SSPs identified, was the availability of assistive devices. Participants reported that assistive devices such as walking sticks and their

wheelchair assisted with managing their balance and fatigue when mobilising outside their homes.

> "Yes, look, I don't go out without it. Here [in the house] I walk around without it, but I don't go out without my cane. Look if I'm in a shop or something, luckily it can fold up…Then I put it in the trolley and hold onto the trolley. So yes, the cane, it's just definitely for safety, because my balance is not quite, and I think … the experts will recommend that one takes the cane with you." [SSP 3]

Occupational therapy participant 1 confirmed that wheelchairs especially facilitate mobility outside the home for stroke survivors.

> "I know one of the reasons why a lot of the patients want their wheelchairs even if they are mobile. A lot of them say they want to use it for going to church." [OTP 1]

4.4 CONCLUSIONS

- To explore the experienced and perceptions of stroke survivors living in the Eastern SD of the Western Cape on reintegrating into their communities using an occupational therapy lens.
- To explore the perceived barriers to community reintegration as experienced by the stroke survivors and community-based occupational therapists in the Eastern SD of the Western Cape.
- To explore the perceived facilitators to community reintegration as experienced by the stroke survivors and community-based occupational therapists in the Eastern SD of the Western Cape.

In this study, most of the SSPs were in their 60s, male, Afrikaans speaking, married, lived with their families, and had not completed high school. Although most of the SSPs had some form of employment prior to their injury, they were not able to return to work after their stroke and therefore all participants were dependent on either a disability grant or state pension as an income. Most of the SSPs had only suffered one stroke, with the most common type being right sided with resultant left hemiplegia. The most prevalent comorbidities included hypertension, diabetes mellites and increased cholesterol. The stroke survivors had been admitted an average of 8 weeks in-patient rehabilitation at WCRC and were 1 year 10 months post discharge.

The OTPs in this study were both young and female. They had been employed at their clinic for longer than one year and had previous work experience in the Department of Health at different levels of care. Both participants expressed an interest in the field of neurology and were seeing stroke patients on a weekly basis. Both participants experienced that stroke survivors were referred during the sub-acute phase of recovery and their treatment session took place at the clinic or in the patient's homes. Their therapy was provided mostly on an individual basis although one OTPs reported running and exercises group for stroke survivors.

In this chapter, three themes emerged from the data collected during the semi-structured interviews. Theme one emerged as the changes that stroke survivors living in the Eastern SD of the Western Cape experienced on returning home and reintegrating into their communities, one to three years after having received intensive in-patient rehabilitation. Stroke survivors reported experienced changes as a result of personal factors, environmental factors and changes within occupations and performance factors. Theme one provided insights into the first part of objective one of this study that aimed at exploring how stroke survivors experienced reintegrating into their communities.

Theme two emerged as the barriers these stroke survivors perceived and experienced when reintegrating into their communities, one to three years after having received intensive in-patient rehabilitation. As with theme one, the SSPs experienced and perceived these barriers as a result of personal factors, environmental factors, and occupational and performance factors.

Theme three emerged as the facilitators that stroke survivors living in the Eastern SD of the Western Cape experience while reintegrating into their communities, one to three years after having received intensive in-patient rehabilitation. In theme three, SSPs mainly experienced intrinsic personal factors and extrinsic environmental factors as facilitators. Theme two and three provided insights into the second part of objective one of this study that aimed at exploring how stroke survivors perceived and experienced the barriers and facilitators to their community reintegration.

Lastly, from the data there emerged the barriers and facilitators to providing a service to help stroke survivors reintegrate into their communities, as experienced by community-based occupational therapists servicing the Eastern SD of the Western Cape. This data obtained was triangulated with data obtained from the SSPs and merged into theme two and three. The data that emerged from the OTPs provided insights into the second objective of this study that aimed

to explore the barriers and facilitators to providing a service to help stroke survivors reintegrate into their communities in the Eastern SD of the Western Cape, as perceived and experienced by occupational therapists in this area.

In the next chapter, the results will be discussed.

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

The purpose of this study was twofold. Firstly, to explore the experiences and perceptions of the factors that influenced the community reintegration of stroke survivors, who had mild to moderate strokes and had received intensive rehabilitation at WCRC prior to going home. Secondly, to explore the perceived barriers and facilitators to community reintegration that stroke survivors experienced in the Eastern SD of the Western Cape. Lastly, the study intended to determine the perceived and experiences barriers and facilitators that occupational therapist encounter while providing services in the same area and to use this to triangulate the data that emerged from the stroke survivor participants.

This chapter will firstly discuss the representivity of the two samples of participants that took part in the study followed by a discussion of the findings in terms of the two mention objectives. This will be done by analysing and contrasting the findings with existing literature.

5.2 REPRESENTIVITY OF THE TWO SAMPLE OF PARTICIPANTS

5.2.1 Stroke survivor participants

The SSP sample in this study consisted of 11 participants, which although small, is consistent with the sample sizes utilised in qualitative research (Creswell, 2014) and is appropriate for relatively homogeneous groups (Hagaman & Wutich, 2017). Even so, the small sample size and specific area in which the research took place, may limit the generalisability of the findings.

The mean age for the SSPs in the study was 56 years, although the median age was 60 years, which is much younger than the mean age of 67 years for stroke survivors reported in South Africa (Ranganai & Matizirofa, 2020), with 54.5% (n=6) of participants in this study were in their 60's. This result concurs with a recent review of the trends of stroke in Africa, which found that many stroke survivors were between the ages of 40 and 60 (Akinyemi et al., 2021) and is similar to the mean age of 54.4 years reported for SSPs in Nigeria (Abubakar & Isezuo, 2012). Another reason for the younger age of the SPPS in this study may be that the participants were recruited from the medical records at the WCRC where younger stroke survivors may be prioritised above older stroke survivors for intense in-patient rehabilitation as they usually achieve better physical outcomes (Seitz & Donnan, 2015).

Of the 11 SSPs that took part in the study, 64% (n=7) of the participants were male. This is contrary to the South African prevalence, where females are reported to be 18.2 times more likely than males to have a stroke (Ranganai & Matizirofa, 2020) but is consistent with several other African countries, such as Nigeria, Sudan and Tanzania, where a higher male prevalence of stroke survivors has been reported (Abubakar & Isezuo, 2012; Akinyemi et al., 2021). Due to the small sample size, no significant indicators could be identified for the higher number of male participants.

Seventy three percent of the participants were married with only 18.2% (n=2) reporting never being married and one being a widower. Similar trends for stroke survivors living in the Western Cape have been reported in other studies where the majority of participants were married (Biggs & Rhoda, 2008; Cawood & Visagie, 2016; Ranganai & Matizirofa, 2020). Of the 11 SSPs, 72.7% (n=8) of participants lived with their partner and/or children and 27.3% (n=3) participants lived with other family members such as parents or grandparents. Living with someone has been associated with increased independence in ADLs and better general health and prognosis than with stroke survivors that lived alone (Rejnö et al., 2019).

Afrikaans was the home language of 90.9% (n=10) of the participants with only one participant whose home language was isiXhosa. Available statistics of the home language of the population of the City of Cape Town state that 34.9% of the population are Afrikaans speaking and 29.3% are isiXhosa speaking (StatsSA, 2011). Although, there are no statistics on language for the Eastern SD as a whole, when considering the language statistics for smaller areas within the Eastern SD such as Eerste River (Afrikaans 73.9%; isiXhosa 8.9%), Kuilsriver (Afrikaans 60.2%; isiXhosa 3.2%), Macassar (Afrikaans 85.2%; isiXhosa 5.0%), Strand (Afrikaans 77.2%; isiXhosa 2.2%), Mfuleni (Afrikaans 3.4%; isiXhosa 85.9%) and Nomzamo (Afrikaans 5.3%; isiXhosa 74.4%) the larger percentage of the population is Afrikaans speaking (StatsSA, 2011). In South Africa, language is often related to different races and the high prevalence of Afrikaans is consistent with the large Afrikaans speaking coloured and white community living in the Western Cape.

Of the SSPs, 9.1% (n=1) participants reported finishing high school which is much lower that the provincial average. For the City of Cape Town metropole of which includes the Eastern SD, statistics indicate that 37.5% of the population have completed secondary school which is slightly higher than the national average of 36% (StatsSA, 2020). The levels of education

achieved been found to influence stroke survivors health literacy (Sanders et al., 2014). Health literacy refers to the ability to gather, understand and apply information regarding a person's health and the services that would promote health (Sanders et al., 2014). A crucial part of rehabilitation post-stroke includes the education of stroke survivors and their caregivers regarding the risks, secondary prevention, and self-management strategies. However, it has been found that stroke survivors with inadequate health literacy show poor retention of the health education provided by healthcare workers (Sanders et al., 2014) and in South Africa a stroke survivors education and health literacy influence the rehabilitation pathway followed (Sanders et al., 2014). Taking into account the importance of education and the ability to retain health related knowledge, it is understandable that lower levels of education are correlated with a higher stroke recurrence (Han et al., 2020). To iterate, not only does educational level affect continued health post stroke but is also associated with the QoL achieved post stroke (Kariyawasam, Pathirana & Hewage, 2020). As a result, SSPs with lower levels of education and inadequate health literacy could have had a negative effect on their health, continued functional improvement post discharge from WCRC and quality of life.

In addition to age and gender being stroke risk factors, several comorbidities emerged during the study. The most prevalent comorbidities reported by the SSPs were hypertension (90,9% of SSPs, n=10), diabetes (54,4% of SSPs, n=6) and increased cholesterol (45,5% of SSPs, n=5). Although these three comorbidities as well as heart problems have been found to be the most common comorbidities associated with stroke survivors in South Africa, Ranganai and Matizirofa (2020) recently reported that diabetes (86,9%) and heart problems (75,7%) are more prevalent than increased cholesterol (47,9%) and hypertension (48,8%) in the stroke population. Uncontrolled blood pressure has also been reported as a significant risk factor for a recurrent stroke (Doogue et al., 2020). Even though SSPs in this study did not indicate if their blood pressure was controlled, 90.9% (n=9) of them had hypertension, putting them at risk of developing uncontrolled blood pressure should they not manage it well. Literature has presented several barriers to the effective treatment of hypertension such as poor service delivery and the limited availability of medication at the primary care level in African countries (Akinyemi et al., 2021) as well as inadequate prescription hypertensives in some developed countries like Ireland (Doogue et al., 2020). In rural South Africa, persons with hypertension have perceived poverty as a barrier to maintaining healthy lifestyles that would improve their blood pressure such as eating healthy and exercising (Jongen et al., 2019). The prevalence of

several co-morbidities and lower levels of education could indicate that the SSPs in this study are at a higher risk of continued health deterioration which in turn would have a direct impact on the community reintegration.

Other comorbidities associated with recurrent strokes are smoking and drinking (Han et al., 2020). While the number of strokes reported by participants varied from 1-5, 63.6% (n=7) of the participants had only suffered one stroke. Initially, the researcher did not intend to include participant with multiple strokes but due to the low numbers of participants identified at the research site, it became necessary. Although three SSPs in this study reported smoking and using alcohol, only one of these participants had had a second stroke. Stroke recurrence could also be due to non-compliance in taking the medication as required, as reported by some of the SSPs sometimes forgetting to take their pills. It is important to note is that the SSPs who survived multiple strokes reported a deterioration in their functioning but were not necessarily re-admitted for rehabilitation after their recurrent strokes.

Slightly more than half the SSPs (54.6%, n=6) had right hemisphere strokes with resultant left hemiplegia while the remaining participants had left hemisphere strokes (27.3%, n= 3), bilateral strokes (9.09%, n=1) or cerebellar strokes (9.1%, n=1). Literature presents differing opinions on the prevalence of left hemisphere versus right hemisphere strokes and the related outcomes. Portegies *et al.* (2015) found when examining cerebral strokes using magnetic resonance imaging, that there is no significant difference in left versus right hemisphere strokes. However, based on the clinical symptoms left hemisphere strokes seem more common, suggesting that left hemisphere strokes usually present with more severe physical impairments than right hemisphere strokes. Hedna *et al.* (2013) reported that left hemisphere strokes are more common and are often more severe with poorer outcomes than right hemisphere strokes. It is important to note that Hedna *et al.* (2013) used several clinical variables and measurement tools such as the National Institutes of Health Stroke Scale to determine outcomes and which have been found to be more sensitive to left hemisphere strokes (Yoo et al., 2010). Based on the above, it can be assumed that left hemisphere stroke survivors may present with more severe physical impairments and therefore not fall into the mild to moderate inclusion criteria for this study. Consequently, resulting in a higher prevalence of right hemisphere stroke survivor participants in this study. In this study, no correlation could be found between the initial CNS score achieved between the different types of strokes.

All SSPs reported in the semi structured interviews an average acute hospital admission period of 4 weeks and 2 days which is double (5-14 days) of what has been reported in other studies conducted in the Western Cape (Cawood & Visagie, 2016; Scheffler & Mash, 2020). This information which could not be verified with the SSPs medical records and may be inaccurate due to a lack of specificity in how the questions were phrased or how the SSPs recalled their hospitalisation. However, according to the SSPs' medical records, the average length of stay for in-patient rehabilitation at WCRC was 54 days, which is also much longer than the 28 days reported in Cawood and Visagie's (2016) study.

Several factors can influence the length of stay such as general medical stability, the speed of functional recovery and the level of independence required prior to returning home. No specific link could be made in this study between the type of stroke, the CNS scores, and the level of functioning on discharge. This could be due to the small sample size. For the purpose of this study the level of functional independence at the time of the interviews was not measure but this could be of interest for future studies, so that a correlation could be explored between various factors such as the type of stroke or initial CNS scores and the level of community reintegration achieved.

One of the consequences of stroke, is the loss of socioeconomic productivity (Akinyemi et al., 2021). Of the SSPs, 90.9% (n=10) were employed prior to injury but only 9% (n=1) were able to return to work. The results concurred with a Western Cape study which (Hassan, Visagie & Mji, 2012) reported that only 9% of participants achieved the rehabilitation outcome level of productive activity (Landrum, Schmidt & McLean, 1995) and were able to return to work. Internationally, similar findings have been reported in Canada, where participants were employed full-time prior to their stroke, but only 8% returned to part time employment and 9% to full-time employment (Teasell, Mcrae & Finestone, 2000). However, a study conducted in the Gauteng province in South Africa, reported that 40% of stroke survivors who completed a work intervention programme returned by six months following their stroke (Ntsiea, van Aswegen & Lord, 2017). No such programme had been offered to the participants of the current study.

As a consequence of not being able to resume the worker role this study found that all the SSPs were in receipt of a disability grant or state pension, confirming the financial burden of stroke in South Africa (Maredza & Chola, 2016) due to the indirect costs associated with disability pay-

outs and low return to work rates post stroke (Louw et al., 2020). It also reflects the change in financial wellbeing reported by some of the SSPs.

This sample of SSPs had the lived experience of the consequences of a mild to moderate stroke for one to three years and had navigated their community reintegration and were therefore able to provide rich data on how their occupational performance had changed and the barriers and facilitators they experienced to their community reintegration (Creswell, 2013).

5.2.2 Occupational therapy participants

At the time of the study there were three occupational therapists employed in the Eastern SD of the Western Cape. While they were responsible for the community work in the district, they also provided services at the CDCs/clinics and one district hospital. While the employment numbers of rehabilitation professionals, especially occupational therapists in comparative districts could not be confirmed, from the researchers experience while working in the Eastern SD, this area was under resourced in terms of human capital and the workload was extremely high.

Of the three occupational therapists only two agreed to participate in the study. Both were female and were 27 and 30 years old. Both OTPs had been employed in their current job for more than one year and had some previous work experience in the domain of physical rehabilitation. The demographic characteristics of these two OTPs are consistent with the those described by Ned *et. al.* (2020), where most occupational therapists in the country are young (between 25 and 30 years) and 95% are female. Although the Western Cape has the second highest number of occupational therapists in the country only 11% are employed in the public sector (Ned et al., 2020). The OTPs both reported a keen interest in patients with neurological problems. Both saw stroke survivors in the community weekly either at the clinics or at patients' homes and reported stroke survivors made up between 40 and 70% of their workload. Ned *et al.* (2020) confirmed that occupational therapists in South Africa often address impairments associated non-communicable diseases such as stroke and treatment is delivered in health facilities or people's homes

While the experience and expertise of the two OTPs allowed for the collection of rich data, the small number was insufficient to allow for data saturation and therefore the perceptions and experiences of these OTP was used to triangulate the findings of the SSPs. Triangulation

provided the researcher the opportunity to explain the result of the study, increase the validity of the results and enrich the research by providing different perspectives (Noble & Heale, 2019).

5.3 DISCUSSION OF THE FINDINGS FROM THE SEMI-STRUCTURED INTERVIEWS

As discussed above, all the participants were survivors of mild to moderate strokes that had received intensive rehabilitation at WCRC between one to three years previously and had returned to their homes in the Eastern SD of the Western Cape. They were all discharged from WCRC with a level III rehabilitation outcome (Landrum, Schmidt & McLean, 1995). As discussed in the literature review, the Western Cape Comprehensive service plan for healthcare (Western Cape Governement, 2006) states that rehabilitation should take place across all levels of care. Literature demonstrates that spontaneous recovery after a stroke takes place within the first three months and then starts to plateau, but training induced recovery is not limited by time and can continue improving long after the incident (Chen, Epstein & Stern, 2010). It is therefore crucial that stroke survivors have a continuum of care after being discharged from in-patient rehabilitation. As can be seen from the literature review there is uncertainty about the nature of occupational therapy invention required to facilitate community reintegration, as proposed by levels III-IV, as well as the health care worker (rehabilitation professional or midlevel worker) best suited to manage this intervention process.

Objective one of this study therefore explored the SSPs' perspective and experiences of the factors influencing their community reintegration.

5.3.1 Stroke survivors living in the Eastern SD of the Western Cape experiences and perceptions of reintegrating into their communities using an occupational therapy lens

5.3.1.1 Changes with personal factors

During the study, SSPs reported changes in their occupational performance due to several intrinsic personal factors. Intrinsic factors that influenced their occupational performance included changes in their physiological, neurophysiological, cognitive, and psychological functioning as well as changes in their spirituality. As with this study, other studies found that the physiological, neurophysiological, and cognitive effects of a stroke impact community reintegration because of the limitations imposed on social engagement, traveling, recreational pursuits and returning to work (Edwards et al., 2006; Walsh et al., 2015).

Stroke survivor participants experienced two main changes due to physical factors. Firstly, participants experienced limited occupational performance due to the loss of endurance and strength. Secondly, SSPs experienced changes in their occupational performance inside and outside their homes due to a loss of mobility.

In the home, SSPs found that they struggle to engage in IADL tasks such as cooking, washing dishes, washing laundry, cleaning, and caring for pets. Outside the home, SSPs also experienced needing assistance to engage in homecare tasks like shopping. Some of the commonly reported IADL tasks that stroke survivors struggle with are washing clothes, cooking, homecare tasks and shopping (Legg, Drummond & Langhorne, 2006; Rhoda, Mpofu & De Weerdt, 2011; Rhoda, 2012). As found in this study, limited independence in IADL tasks and subsequent community reintegration by rendering stroke survivor's dependent on caregivers for assistance (Rhoda, Mpofu & De Weerdt, 2011).

On top of the loss of strength and endurance, SSPs reported the loss of independent mobility. Firstly, participants found that they were dependent on other to propel their wheelchairs, especially outside. Secondly participants found that they could no longer walk independently or use other modes of transport such as riding a bike, driving, or using public transport. As a result of these limitations participants became dependent on friends or family to mobilise outside their homes and for transportation. Consequently, affecting their ability to engage in activities such as going to the shop or bank, attending sport and social events, and going for health-related appointments. Similarly, dependence on others to participate in community activities was reported by SSPs in a study conducted in Kwazulu-Natal. Several studies have reported that a loss of independent mobility affect stroke survivors ability to leave their homes and participate in social events (Rhoda et al., 2015; Tashiro et al., 2019) and result in a decreased sense of autonomy and independence (Moeller & Carpenter, 2013; Govender et al., 2019; Bello et al., 2020).

Besides the physical factors that emerged in this study, SSPs reported an increased dependence on family and friends due to residual cognitive deficits. Stroke survivor participants in this study found that memory loss and speech limitations increased their dependence on others with activities that required good communication such as shopping or participating in religious activities. Participants also found that they became dependent on other to assist them in remembering important dates or to help with everyday problem solving. Cognitive deficits

such as memory loss and speech deficits are common secondary effects of stroke and are often more subtle than the physical side-effects (Turner et al., 2019). Walsh *et al.* (2015) reported that the poor understanding of more subtle symptoms such as fatigue and speech impairments by others in the environment can lead to stroke survivors experiencing social stigma resulting in social isolation as experienced by some participants in this study. Memory loss has been found to make stroke survivor's feel detached from others due to a decreased sense of time and context (Moeller & Carpenter, 2013), increase caregiver strain (Scheffler & Mash, 2019) and decrease life satisfaction (Edwards et al., 2006).

Although not mentioned by SSPs, OTPs reported that often persons with cognitive deficits were hidden by their families. Although not specific to cognitive fallouts, Elliot *et al.* (2019) reported that persons with neurological disabilities are sometimes concealed by their families and socially excluded from family and community events and activities. Interestingly, most studies in Elliot *et al.'s* (2019) scoping review report that concealment took place in rural areas whereas the Eastern SD is viewed as an urban area (Western Cape Government, 2014b). One plausible reason for this stigma could be due to the migration of people from more rural provinces like the Eastern Cape to the Western Cape of which many have lower than matric education (StatsSA, 2015) and poor health literacy including a lack of knowledge regarding the disease (Elliot et al., 2019).

Common psychological changes reported by stroke survivors are feelings of frustration (Walsh et al., 2015; Turner et al., 2019), anger (Walsh et al., 2015; Turner et al., 2019), lability (Turner et al., 2019), mood swings (Magaard et al., 2018; Turner et al., 2019), irritability (Turner et al., 2019), a lack of empathy (Turner et al., 2019) and a loss of confidence (Walsh et al., 2015; Turner et al., 2019). In addition, SSPs in this study reported feeling of bitterness, disappointment, and shame, mainly in response to being dependent on others for basic tasks such as basic self-care which challenged their dignity and humanity. Psychological factors post stroke have a direct impact on community reintegration such as struggling to work due to a lack of confidence, mood and emotions affecting relationships and also avoiding social activities (Turner et al., 2019).

As can be seen, literature recurrently emphasises that stroke survivors need to engage in meaningful activities after a stroke. It is therefore not a surprise that SSPs in this study experienced challenges in accepting the loss of function and by implication the permanence of

their disability. Several studies had explored the cycle of acceptance of the disability that stroke survivors go through and have found that stroke survivors experience an initial phase of feeling overwhelmed and fearful, followed by a period of sorrow due to the functional loss experience and lastly gradually accept their disability and finding new ways to reengage in their previous activities and life (Hole et al., 2014; Pallesen, 2014). According to Moeller and Carpenter (2013), it is most difficult to accept the loss of function and disability, if the skills lost affects participating in self-defining activities. Turner *et al.* (2019) further confirmed that many stroke survivors experienced a loss of identity and struggled to accept their diagnosis and resultant disability. This loss of participation in self-defining activities, fulfilling previous roles and being contributing members of their society is often results in a loss of identity. This could possibly explain why SSPs in this study reported limited feeling resigned to their fate and an inability to change things due to their limited community reintegration.

In addition to concerns relating to the loss of function, participants reported worrying about the future. This was predominantly due to limited community reintegration in terms of generating an income again and the resultant loss of income. Stroke participant highlighted concerns about paying debts and surviving in the future where they might need financial support from others as well as having to adjust to a way of living with a much-reduced income. The loss of income associated with stroke is especially prevalent in developing countries such as South Africa (Maredza & Chola, 2016) placing a high burden of care on caregivers (Scheffler & Mash, 2020) and the state in the form of a disability grant or pension payments (Maredza & Chola, 2016; Louw et al., 2020).

Lastly, participants reported on the spiritual changes that they experienced, either questioning their beliefs systems or feeling disappointment in the spiritual support they received versus finding their belief system as a source of strength. Literature highlights that higher levels of community participation in activities such personal relationship, work, recreation and spirituality are linked with higher QoL post stroke (Mayo et al., 2002). Giaquinto, Spiridigliozzi and Caracciolo (2007) found that there is an association between faith and emotional distress in stroke survivors while other studies have reported that spiritual activities and belief systems can bring a sense of strength and peace for stroke survivors as well as help them to adapt to their new circumstances (Ratna, 2018; Azar, Radfar & Baghaei, 2020), therefore facilitating community reintegration. In contrast, Omu, Al-Obaidi and Reynolds (2014) found that religious faith had no significant effect on Muslim stroke survivors' self-efficacy or life satisfaction in

Kuwait. Although the nature of the SSP's religious beliefs were not explored, the Muslim faith is prevalent in the area of this study (StatsSA, 2013).

5.3.1.2 Changes in environmental factors

Stroke survivor participants experienced changes with environmental factors in two main areas after their stroke which they perceived to have influenced their community reintegration.

Firstly, participants experienced that their social environment changed. Some participants experienced decreased social involvement from family and friends as well as changes in the attitude from community and family members. Both were reported to have resulted in social isolation. Participants perceived that some of their friends and or family communicated less with them, others no longer came to visit, and they could no longer engage in activities such as church because their family members were unwilling to take them. Social isolation has been listed as one of the prominent challenges often experienced by stroke survivors when returning home (Moeller & Carpenter, 2013) as a result poor social support systems (Cawood & Visagie, 2015; Rhoda et al., 2015). High QoL has been correlated with social participation (Moeller & Carpenter, 2013; Chou, 2015; Bello et al., 2020) and stroke survivors who experience social isolation have been reported to be at risk of feeling angry, depressed, frustrated and dissatisfied (Dowswell et al., 2000; Cunningham & Rhoda, 2014).

In contrast, some SSPs experienced the support of their family and friends as positive. Participants reported family members and friends being willing to come fetch them for social events and that this support and assistance encouraged them to engage independently in social activities like vising friends and neighbours. In agreement, Walsh *et al*. (2015) argues that the practical and emotional support received from their friends and family encouraged participation in meaningful activities and allowed stroke survivors to be more independent and involved.

Secondly, participants experienced that inaccessible structural layout in their homes and communities restricted their mobility, homecare, selfcare and leisure participation. This was further exasperated by inaccessible natural environments around their homes and in the community. As a result, participants started to avoid tasks and occupations, handing these over to others or becoming dependent for assistance.

5.3.1.3 Changes with occupational and performance factors

The last area that strokes participants experienced changes in after returning home was in their occupational participation and performance. Two main areas of occupation that were affected, were the ability to generate an income and participation in leisure activities.

Participants experienced that they had limited engagement in leisure activities and social engagements were limited to their home. The SSPs perceived the reasons for this was their inability to self-propel their wheelchairs outside, inaccessible surroundings, poor public transport and family members being unwilling to take them somewhere. Decreased engagement in leisure activities has been associated with lower health related QoL reported by stroke survivors (Algurén et al., 2012).

Evidence supports the use of occupation-based intervention by occupational therapist to increase stroke survivors' participation in leisure activities (Wolf et al., 2015). In contrast, this study found that limited, if any, attention was given to addressing leisure with stroke survivors, due to the perception of OTPs that stroke survivors participated in very limited leisure related activities prior to their stroke. There is limited literature that explores leisure participation of adults in South Africa. A study conducted by Vincent-Onabajo and Blasu (2016) explored the leisure participation pre and post stroke for stroke survivors in Nigeria. This study found that prior to their strokes, participants mostly engaged in leisure activities that fell in the social domain, such as spending time with family and talking to friends while they least participated in productive creative leisure activities such as drawing or painting. Similar trends were observed after their stroke though at a lesser scale (Vincent-Onabajo & Blasu, 2016). Furthermore, a study conducted in South Africa on leisure participant of elderly people found that many perceived spiritual activities such as going to church or praying as a form of leisure (Mthembu & Ferus, 2015). It could therefore be that OTPs in this study failed to recognise activities such as social interactions with friends and families or attending church as a form of leisure, therefore feeling that stroke survivors in their areas participated in limited leisure activities prior to their strokes.

Limited return to work by stroke survivors has been confirmed in several studies (Hassan, Visagie & Mji, 2012; Gretschel, Visagie & Inglis, 2017) , which was highlighted again in this study. Participants experienced that the inability to work contributed to their worry about the future and the loss of their role of breadwinner. As can be seen with the demographic

information, 90.9% of SSPs had some form of employment prior to their stroke even though they were nearing the age of retirement, but only one participant was able to return to work. Many of them were self-employed or employed on an informal basis and the end of their working life may possibly not have been restricted to the age of 65, but the stroke resulted in a sudden loss of income irrespective of age. Similar concerns regarding fulfilling the role of breadwinner and caring for family members post stroke was reported by Rhoda *et al.* (2015) in a study conducted in Rwanda, Tanzania and South Africa.

Other changes in roles were the loss of the role of helper/ carer and authority figure due to the reassignment of the homecare/parent role. Changes in role assignment and specifically loss of valued roles have been reported to lead to stroke participants perceiving themselves as ill, not useful and disabled (Rhoda et al., 2015). Alternatively, OTP 1 experienced that elderly stroke survivors often reassigned their homecare role willingly due to cultural expectation that their children should care for them.

The last changes in occupational performance experienced by SSPs was the need to adjust how they completed tasks. This included adjusting to the loss of sensation and taking longer to complete tasks. Some participants also adapted by requesting family members to complete portions of a tasks such as peeling vegetable when cooking. No mention was made of the use of assistive devices except for mobility devices and a bath board. During the acute phases of stroke recovery, rehabilitation focusses on improving body functions but as recovery progresses to the chronic phase treatment needs to focus more on activities and participation (Winstein et al., 2016). It is therefore essential that an occupational therapist's treatment is occupation based which includes providing appropriate assistive devices and practice using these, which would increase independence in the home environment. Prioritising home visits would promote continued care and carry-over of treatment into the home (Naidoo, Van Wyk & Joubert, 2016).

5.3.2 To explore the perceived barriers to community reintegration as experienced by the stroke survivors and community-based occupational therapists in the Eastern SD of the Western Cape.

Often when stroke survivors return home after rehabilitation, they are reported to experience challenges in reintegrating into their homes and communities (Joseph & Rhoda, 2013). Similarly, occupational therapists also experience barriers in providing a service that facilitate

community reintegration (van Stormbroek & Buchanan, 2019). To provide a comprehensive service that is person centred, it is important that occupational therapists understand what these barriers are for stroke survivors so that they can negotiate or accommodate these challenges when providing therapy. Barriers to community reintegration were identified in two main areas, personal factors, and environmental factors.

5.3.2.1 Personal factor barriers

The barriers to community reintegration due to personal factors, as identified by this study, are similar to what is reported in the current literature for developing and developed countries (Edwards et al., 2006; Moeller & Carpenter, 2013; Walsh et al., 2015). Common physiological, neurophysiological and cognitive side-effects of stroke identified in literature are decreased mobility, limited hand function, visual limitations, speech deficits, reduced attention and concentration deficits (Edwards et al., 2006; Cawood & Visagie, 2015; Walsh et al., 2015; Ntsiea, van Aswegen & Lord, 2017) also emerged in this study.

In this study, SSPs experienced a loss of physical strength and endurance. Associated with unilateral upper limb weakness is poor grip strength, which participants reported to specifically affect activities that required bilateral upper limb integration. In turn, SSPs struggle to participate in IADLS such as washing dishes, shopping for groceries, managing money and engaging in leisure activities like playing guitar. Rhoda (2012) reported similar difficulties in the performance of daily activities due to poor grasp. On the other hand, unilateral lower limb weakness affected participation in IADL such as cleaning, gardening, and washing dishes in standing or engaging in leisure activities like dancing. Reasons provided were the inability to stand for long, low endurance and tiring quickly and the inability to move like before.

The prevalence of poor endurance and fatigue post stroke and the influence it has on occupational performance has been discussed in several studies (Ntsiea, van Aswegen & Lord, 2017; Magaard et al., 2018; Turner et al., 2019; Almhdawi et al., 2021). Fatigue is often one of the most severe symptoms reported by participants that have suffered from a mild stroke (Worthington et al., 2017; Magaard et al., 2018) influencing stroke survivors physical activity, cognitive abilities (Almhdawi et al., 2021) confidence (Turner et al., 2019; Aarnes, Stubberud & Lerdal, 2020) and mood (Turner et al., 2019; Aarnes, Stubberud & Lerdal, 2020). Furthermore, fatigue can lead to an avoidance of activities (Aarnes, Stubberud & Lerdal, 2020) and even for

those with mild physical impairments, fatigue can hinder involvement in family commitments (Turner et al., 2019) and returning to work (Ntsiea, van Aswegen & Lord, 2017).

In addition to decreased strength and endurance, SSPs experienced the loss of mobility as a barrier to community reintegration. Studies have found that poor mobility limit independence in self-care such as accessing toilets, often increase confinement to bed and increasing the strain on caregivers (Visagie & Swartz, 2016; Scheffler & Mash, 2019). Three physical factors emerged that influenced mobility. Firstly, due to unilateral weakness and poor grip strength, stroke survivors reported an inability to self-propel their wheelchair outdoors. Wolf *et al.* (2015) found that stroke survivors had poor wheelchair mobility skills due to a lack of proper training. This could be a plausible reason, as foot propelling is a compensatory method for wheelchair propulsion in the absents of unilateral grip strength. Secondly, lower limb weakness influenced gait as well as participants ability to make use of public transport due to the high step into a taxi. Thirdly, neurophysiological factors like were poor balance, visual deficits, and residual epilepsy affected gait with a resultant loss of independent mobility inside and outside their homes.

Additional to the physical barriers presented to mobility, SSPs also experienced psychological barriers such as the fear of falling or having a fit in public hindered mobility. Several studies have confirmed the fear of falling as a barrier to community reintegration (Wood, Connelly & Maly, 2010; Govender et al., 2019). In Japan, Tashiro *et al.* (2019) found that stroke participants' mobility is frequently constrained to their home or immediate neighbourhood due to poor gait speed and a fear of falling. Participants were unable to access community facilities and had a significant loss of life-space mobility. Similarly, in this study, SSPs experienced avoidance of engaging in tasks alone such as bathing or showering and no longer attended activities outside their home for fear of falling or fitting. Occupational therapy participants confirmed that in their experience limited mobility skills result in stroke survivors becoming dependent on others to complete tasks or to mobilise outside their homes.

Stroke survivor participants also experienced several cognitive factors that presented as barriers to their community reintegration. Participants found that memory loss and forgetfulness as well as speech impairments made them more dependent on family and friends when attending health related appointments, participating in religious activities or to engage during social events. These findings support the existing evidence that poor memory, decreased

attention and concentration, difficulties with executive functioning and language fallouts are common effects of a stroke (Edwards et al., 2006; Walsh et al., 2015; Turner et al., 2019) that specifically affect community reintegration (Walsh et al., 2015).

Another personal factor that has been found to be a barrier to community reintegration is the loss of motivation that is often a residual effect of a stroke (Mayo, Bernhardt & Zorowitz, 2016). Both SSPs and OTPs in this study identified the loss of motivation as a barrier to community reintegration. Mayo, Bernhardt and Zorowitz (2016) found the lack of motivation to be one of the prominent barriers to successful home integration that is often ignored during rehabilitation. This lack of motivation is of concern as it often drives the desire to make lifestyle changes and engage in health stimulating activities such as exercise, which are important for the prevention of secondary complications and recurrent strokes exercise (Walsh et al., 2015). The frustration at being unable to engage in desired activities reduces stroke survivors motivation to engage in physical and social activities (Wood, Connelly & Maly, 2010) while the success they experience provides the motivation to continue with successful recovery (Hole et al., 2014). The lack of motivation can also be associated with the depression that SSPs often experience in their acute phase post stroke, during the process of coming to terms with their disability and mourning the loss of their previously valued occupations (Kamel et al., 2010; Winstein et al., 2016).

Although SSPs in this study did not mention a loss of confidence specifically, they did articulate the experience of a fear of falling and feeling uncertain about their abilities. This in turn led to them avoiding activities such as going to church and taking others with them to ensure that they did the right thing. Turner *et al.* (2019) reported that a loss of confidence often leads to stroke surivors withdrawing from interactions, social activities, and hobbies. Similarly, OTPs found that stroke survivors sometimes did not have the internal motivation to engage in activities in their communities and preferred to stay at home. Plausible reasons could also be the perceived loss of engagement in meaningful roles (Wood, Connelly & Maly, 2010).

The last personal factor identified as a barrier in this study was the severity of the stroke and the risk of further strokes, as highlighted by the OTPs in the study. During the study this was observed, as SSP 1 who had suffered a mild stroke and achieved an outcome level 3 on discharge with good functional mobility was able to return to work. In contrast, SSP 11 suffered a moderate severity stroke also achieved an outcome level 3 on discharge from WCRC but had

suffered a second stroke on returning home and was subsequently dependent on his wife for assistance with ADL and IADL tasks. Literature confirms that stroke survivors with more severe initial impairments recover less (Prabhakaran et al., 2008) while those with less severe cognitive and physical impairments have a higher probability of recovery and returning to activities such as work (Hassan, Visagie & Mji, 2012).

5.3.2.2 Environmental factor barriers

The second area that SSPs found to be a barrier to community reintegration was due to environmental factors.

Throughout this study and this discussion, the impact of physical impairments on mobility has been highlighted. However, it is important to note that there are other environmental factors that also affect mobility such as inaccessible transport. The inaccessibility of public transport for stroke survivors has been identified in several studies (Cawood & Visagie, 2015; Walsh et al., 2015; Chimatiro & Rhoda, 2017) and also emerged in this study, is applicable stroke survivors living in the Eastern SD of the Western Cape.

Stroke survivor's experience was that taxi drivers are often rude and unwilling to stop or they struggled to get into the taxi without assistance. Similar findings were reported in another study conducted in the Western Cape were participants reported struggling to get the CHCs as taxi drivers were unwilling to pick them up (Kahonde, Mlenzana & Rhoda, 2010). This in turn led to participants paying exorbitant fees to hire private transport (Kahonde, Mlenzana & Rhoda, 2010). Additionally, in Kwazulu-Natal, stroke survivors experienced it challenging to manoeuvre over the natural terrain to get to public transport (Govender et al., 2019). Occupational therapy participants also highlighted that taking assistive devices onto taxi's can be challenging and stroke survivors are often dependent on family members to bring them to CHCs for appointments. The one alternative transport available to PwD in the Western Cape metropolitan area is Dial-A-Ride (City of Cape Town, 2022), but in the researchers experience this service is inundated with long waiting lists.

Although in this study participants did not mention uneven terrain as a barrier to accessing public transport, the natural environment was experienced as a barrier to mobility in the community. Several SSPs reported that uneven terrain and long travel distances decreased their independent community mobility. To substantiate, challenges in manoeuvring uneven

ground has been found to increase stroke survivors' dependence on other for fear of falling (Cunningham & Rhoda, 2014). In addition to SSPs experiences, OTPs found that flooding, poor drainage in the streets, a lack of ramps, insufficient sidewalk areas and too high curbs in the communities made it very difficult for stroke survivors to propel their wheelchairs independently. Comparative environmental barriers to community reintegration such as inaccessible pathways and long travel distances have been identified in other South African provinces such as the Eastern Cape (Cunningham & Rhoda, 2014) and other African countries such as Rwanda (Urimubenshi & Rhoda, 2011) and Malawi (Chimatiro & Rhoda, 2017).

In additional to the natural barriers, inaccessible structures in public buildings have often been identified as an environmental barrier to community reintegration (Urimubenshi & Rhoda, 2011; Chimatiro & Rhoda, 2017). As in this study, stairs have been highlighted as an environmental barrier by several studies conducted in the Western Cape (Rhoda, Mpofu & De Weerdt, 2011; Cawood & Visagie, 2015), other provinces (Visagie & Swartz, 2016; Govender et al., 2019) and other African countries (Muli & Rhoda, 2013; Chimatiro & Rhoda, 2017). Structural challenges in patients' homes make it especially challenging for occupational therapists to facilitate community reintegration because as reported, the patient cannot mobilise in or outside their houses due to stairs or narrow passages.

Structural challenges were not only reported in participants homes but also in the health clinics. One of the clinics mentioned in this study, housed the rehabilitation service on the second floor that could only be accessed with a lift that was often not functional. Although the accessibility of CHCs in the Cape Town area have been found to be generally good, some structural challenges have been reported such as inaccessible toilets (Kahonde, Mlenzana & Rhoda, 2010). Other participants struggled to access public areas like a library that only had stairs. The Bill of Rights in the South African Constitution states that "everyone has the right to an environment that is not harmful to their health or wellbeing" (*The Constitution of the Republic of South Africa, Act 108 of 1996*, 1996: 9) and the National Building Regulations and Building Standards Act 103 states that PwD should be able to safely go into a building and access all the facilities inside (*National Building Regulations and Building Standards Act 103 of 1977*, 2008). Therefore, challenges as experienced by participants in this study, indicate that despite regulations being in place, the implementation and control are currently lacking. Also pertaining to challenges for PwD regarding public space accessibility, SSPs in this study experienced a

lack of prioritisation of persons with mobility limitations at service centres such as the SASSA offices. This was confirmed by the OTPs that rendered services in the same area.

Additional environmental barriers to community reintegration found during this study was the poor coordination at the point of discharge and follow-up rehabilitation at the PHC level. Stroke survivor participants experienced challenges in accessing further therapy at their nearest clinic after being discharged from WCRC and accessing other community services like a disability grant. Literature hights several reasons for the lack of continued rehabilitation of stroke survivors at community level in South Africa (Govender et al., 2019), and in the Western Cape (Scheffler & Mash, 2019) which are enumerated below.

The first barrier often relates to how referrals between health care providers take place as well as how booking systems are run at community level. Current literature provides reasons such as a lack of referral from tertiary hospitals to community service providers (Govender et al., 2019; Scheffler & Mash, 2019), some referral forms do not indicating occupational therapy as an option (SA Department of Health, 2018) and follow-up appointments are poorly scheduled (Mlenzana et al., 2013). In this study, SSPs found that rehabilitation staff were not at the clinics, and they were unable to get an appointment.

As highlighted in the literature review, there is a shortage of occupational therapist in the public sector, especially at PHC level (Govender et al., 2019; Jejelaye, Maseko & Franzsen, 2019; Tiwari, Ned & Chikte, 2020). As a result, community occupational therapist are required to provide services at multiple facilities (Naidoo, Van Wyk & Joubert, 2016; Visagie & Swartz, 2016; Scheffler & Mash, 2019). In the researchers experience while working in the community, administration staff also do not manage the booking systems well, resulting in overbooking clinic days when the therapist is not on site at the clinic. This results in in-efficient service delivery. As a consequence of this therapists prefer that appointments are made directly with them, which in turn makes it difficult to book appointments when the therapist is not at a specific facility.

Similar to the researcher's experience of poor booking systems in the clinic, OTPs in this study reported challenges at the clinics due to long waiting times for files and other medical appointments clashing with rehabilitation times. Further highlighting the lack of organisation sometimes found in the clinics. It is also important to note that this study took place during the COVID-19 pandemic, during which many healthcare services were de-escalated to the bare

minimum and many rehabilitation workers were relocated to other tasks such as contact tracing and assisting at vaccination centres. Other repercussion related to the COVID-19 pandemic were the lockdown regulations, restricting the number of people in a single venue. Many group treatments were therefore cancelled, as also reported by SSPs who attended stroke groups less regularly due to these restrictions.

Another barrier to accessing follow-up rehabilitation services was that the clinic was far away and SSPs could not afford the taxi fees to get there. These findings are in agreement with Cawood and Visagie (2016) who found that stroke survivors did not receive continued therapy because of a lack of referral and transport barriers.

The last barrier to accessing continued rehabilitation was that some of the SSPs who did receive some form of therapy reported non-attendance of or stopped attending because they felt the therapy given was not appropriate to their needs. They also felt that it was not useful and was not person centred. Believing that therapy is ineffective, not applicable or that the therapist is incompetent contributes to stroke survivors to not continue accessing the rehabilitation services that could facilitate their community reintegration. As highlighted by Mlenzana *et al.* (2013), rehabilitation that is not personalised to the needs of the users presents as a barrier to accessing the service. In summary, despite the fact that training induced recovery post stroke can be facilitated past the acute phases of a stroke (Chen, Epstein & Stern, 2010), the fact that stroke survivors are not receiving continued intervention at community level indicates this is not taking place.

As presented in the literature review, the Western Cape Health Service Delivery Platform 2030 Policy (Western Cape Government, 2014a) states that rehabilitation services PHC level should focus on body structure and function impairments which can be resolved quickly, and service delivery should include the provision of assistive devices like mobility aids. Furthermore, it states that services at this level rehabilitation is nurse driven with a core team consisting of clinical nurse practitioners supported by a medical officer. One of the major concerns in how this policy describes PHC rehabilitation services is that it gives no clear indication of the role of rehabilitation personnel such as physiotherapists, occupational therapist, and speech therapist except for playing a supportive role to the nurse practitioners and medical officers. The vague description provided also raise questions regarding the competence of nurses to provide rehabilitation and prescribe assistive devices with their “basic knowledge and skills in

rehabilitation" (Western Cape Government, 2014a: 53). As can be seen from the results in this study, community-based rehabilitation of stroke survivors needs to be personalised, take place in the home, and focus on overcoming the social determinants of health presenting as a barrier to community reintegration. The notion that such a service can be provided by staff not trained in this area is concerning.

Moreover, task shifting to midlevel healthcare workers has been proposed as a way to increase service delivery in areas that have a limited number of occupational therapists (Bryer et al., 2010; Naidoo, Van Wyk & Joubert, 2016). Similar reasoning can be observed in the Western Cape Health Service Delivery Platform 2030, which states that home and community-based care services will be provided by a core service team consisting of CHWs (Western Cape Government, 2014a). Nonetheless, the efficacy of this has not yet to be proven and it could be argued as a contravention of stroke survivors rights to accessing services as currently CHW's do not have the skills and knowledge to provide such as services (Scheffler & Mash, 2019, 2020).

In addition to not accessing rehabilitation services, SSPs also struggle to access other community services such as disability grants. Experiences of the SPPs were the lack of information or misinformation regarding these services, being provided by healthcare providers. Occupational therapy participants noted that patients often didn't know how to apply for a disability grant, resulting in them needing to facilitate this process which was often a challenge as the nearest office was in another town. Wegner and Rhoda (2015) highlighted that not all families are aware of disability grants, some PwD lack personal identification documents and travelling to and process to obtain these documents is a challenge. Several studies have reported a lack of information regarding continued health care and support services in the community is being provided to patients on discharge (Kahonde, Mlenzana & Rhoda, 2010; Walsh et al., 2015). This in turn can result in a challenge to continued therapy (Walsh et al., 2015; Turner et al., 2019). The lack of continued rehabilitation and difficulty in accessing services post discharge from WCRC, indicate current gaps in how discharges of stroke survivors are taking place at WCRC.

Another environmental barrier that emerged was the lack of or excessive social support from family. Stroke participants as well as OTPs experienced that often families are overprotective, not allowing stroke survivors to engage in activities independently. Over supportive families can

result in dependency as well a stroke survivors feeling like a burden and having a decreased sense of control over their lives, which is observed as a barrier to community reintegration (Wood, Connelly & Maly, 2010; Cawood & Visagie, 2015; Walsh et al., 2015). On the other hand, SSPs were unable to go to activities due to family members not being willing to take them or assist them. Occupational therapy participants confirmed experiencing this lack of social support from families.

In addition to the lack of social support, two contradicting cultural factors acted as barriers to community reintegration. Some stroke participants reported not wanting help and fearing the community's attitude, which prevented them from asking for assistance. On the other hand, SSPs did not engage in activities because they felt there was someone else who could do it. This latter attitude was confirmed by OTPs who found that often, especially with elderly, stroke survivors would expect family members to do most tasks. The taking on of this sick role could be associated with the loss of motivation or depression, as discussed under personal factors.

Another environmental barrier identified by both SSPs, and OTPs was the loss of finances which limited engagement in previous leisure activities and made it challenging to cover basic costs like accommodation and food. Scheffler and Mash (2020) found that the loss of income had even wider repercussions, as some caregivers needed to resign from their employment to assist stroke survivors, further adding to the financial burden of the household.

The last environmental barrier that emerged during the study was having inappropriate devices or experiencing problems with the devices that SSPs were issued. For example, often stroke survivors with unilateral weakness are provided with a low-slung wheelchair which allows them to self-propel using one hand and one foot. Stroke survivor participants found it frustrating to propel their wheelchair in this way due to the slow speed and difficulty in managing uneven terrain, therefore expressing a desire for a motorised wheelchair. Similarly, Govender *et al*. (2019) found that wheelchair-bound individuals often become homebound and isolated due to their decreased functional mobility. Other participants reported having a walking frame but due to living on the third floor were unable to use it to mobilise outside.

In a study conducted by Naidoo, Van Wyk and Joubert (2017) in KwaZulu-Natal, PwD specifically expressed a need that occupational therapists to provide appropriate assistive devices. Sometimes assistive devices issued are appropriate only for certain circumstances and therapist need to consider a holistic view where and what for the devices will be used. From

the OTPs' perspectives in this study, challenges were experienced in not having stock of the appropriate assistive devices for their patients, the available assistive not being adjustable or appropriate for the clients' homes and not having a wide variety of devices on tender. The devices mentioned by SSPs during this study were mainly mobility devices, such as wheelchairs, walking frames, walking sticks and elbow crutches. The only non-mobility device mentioned was a bath board. This could be an indication that a limited range of assistive devices are being issued at community level, especially devices that could facilitate participation in homecare activities (Jejelaye, Maseko & Franzsen, 2019). Alternatively, it could indicate that occupational therapist's treatment is more physical in nature and less focused on the occupations which would enhance community reintegration. Although, in the researchers experience while working for the Department of Health, a wide variety of assistive devise available on tender but due to the budget constraints, mobility device were often prioritised.

The lack of appropriate assistive devices at PHC level in South Africa has been highlighted by several studies (Wegner & Rhoda, 2015; Jejelaye, Maseko & Franzsen, 2019). Medical services are often prioritised leaving limited financial resources for assistive devices (Ned, Cloete & Mji, 2017). In the researchers experience while working at WCRC, low slung wheelchairs were issued to stroke survivors by occupational therapists and physiotherapist. These devices are best suited for users with hemiplegia, as many stroke survivors present, but are difficult to propel over uneven terrain and are slower due to being foot propelled. Other devices that would increase users speed and be better suited for uneven terrain, such as motorised wheelchairs or scooters were unavailable for different reasons. At the hospital, due to limited stock and budget constraints, motorised wheelchairs were allocated to patients with more severe mobility limitations such as quadriplegic spinal cord injuries. On the other hand, cheaper alternatives such as scooters were not on tender and too expensive for families to afford. Therefore, therapist issued low-slung wheelchairs even though outdoor mobility is not optimal with this device.

5.3.3 To explore the perceived facilitators to community reintegration as experienced by the stroke survivors and community-based occupational therapists in the Eastern SD of the Western Cape.

Many personal factors, environmental factors and occupational performance factors can be both a barrier or facilitator (Mlenzana et al., 2013). During the study the absence of certain

factors presented as a barrier whereas the presence of the same factors presented as a facilitator to community reintegration for stroke survivors.

5.3.3.1 Personal factor facilitators

One of the facilitators to community reintegration identified by SSPs was having attended in-patient rehabilitation. Ned, Cloete and Mji (2017) argued that one of the main aims of rehabilitation is to increase participation in all aspects of the community and in doing so improving wellness and QoL. Furthermore, a strong correlation has been found between the intensity of rehabilitation that stroke survivors receive and the functional recovery that they make (Foley et al., 2012). Stroke survivor's that receive regular occupational therapy are reported to achieve higher levels of functional independence (Foley et al., 2012). In agreement, OTPs found that stroke survivors who have attended in-patient rehabilitation and were more mobile, achieved better levels of community reintegration such as returning to work. Reasons for this could be that in the South African context out-patient rehabilitation at the community level is often not delivered with the same intensity as in an in-patient rehabilitation setting (Bryer et al., 2010). Based on the evidence that the amount of occupational therapy treatment time correlates with functional gains made (Foley et al., 2012) it can be deduced that stroke survivors that have had the opportunity to receive more intensive in-patient rehabilitation should present with better functional outcomes than their counterparts that only receive sporadic out-patient rehabilitation at their nearest clinic. In the Western Cape and in the Easter Cape having received assistance from a health professional has been reported as an environmental facilitator to community reintegration (Kahonde, Mlenzana & Rhoda, 2010; Cawood & Visagie, 2015).

Some of the skills SSPs reported having practiced during in-patient rehabilitation was improving gait and practicing functional mobility such as managing stairs and getting into a taxi. In turn, the ability to independently mobilise, drive and use public transport when returning home was found to facilitate community reintegration, allowing SSPs to mobilise independently in their homes or go out for appointments or events. The results are in agreement with studies conducted in Africa (Bello et al., 2020) and Taiwan (Chou, 2015) where improved mobility skills were associated with higher levels of QoL experienced by stroke survivors.

In addition to the physical factors, participants perceived their belief system as a facilitator to community reintegration. Participants experienced their belief systems as a source of

encouragement while trying to regain function as well as a giving them peace when they worried about the future. In agreement OTPs also found that stroke survivors' churches were a source of support and an opportunity for social interaction. Most known studies in South Africa have explored how PwDs' and their communities' belief systems influence their understanding of the causes of neurological conditions such as stroke, and the subsequent behaviour regarding accessing health care (Brainin, Teuschl & Kalra, 2007; Wegner & Rhoda, 2015; Rohwerder, 2018; Elliot et al., 2019). However, studies exploring how belief systems influence stroke survivors' mood, motivations and occupational participation is limited. Azar, Radfar and Baghaei (2020) found that in Iran, stroke survivor's belief system influenced how they managed, accepted and adapted to their injuries. For example, their religious beliefs and practices provided motivation to increase self-care and fulfil occupational roles, reduced stress, increased adaptability, and provided a more positive outlook on their injury while enhancing their ability to endure the physical challenges experienced (Azar, Radfar & Baghaei, 2020). Similar findings were reported in Indonesia, where stroke participants reported experiencing support for their suffering and peace through prayer and worship and being able to accept and adapt to their physical challenges as a result of their belief system (Ratna, 2018).

Lastly, SSPs perceived feeling motivated as a facilitator to community reintegration. Walsh *et al*. (2015) argued that by being able to help others, stroke survivors can reduce the stress of being a burden and in turn be motivated to participate in activities. Similarly, in this study, having dependents directly influenced SSPs' motivation. Stroke participants who were breadwinners or primary caregivers prior to their stroke were highly motivated to regain functional independence. Stroke survivor participants that were more motivated continued with exercises at home and attempted to complete tasks independently stated that they did not want help. In agreement, OTPs found that patient's motivation played a large role in compliance with therapy and the carryover of skills to the home environment.

5.3.3.2 Environmental factor facilitators

Although many SSPs reported the lack of social support from family as a barrier to community reintegration, some found that the decreased social support from family became a facilitator. This was because they were then forced to attempt tasks independently. On the other hand, most stroke survivors perceived the social support that they received from their family and community as a facilitator. This was due to the encouragement they received as well as

practical support. Families can play an important role in how stroke survivors reintegrate into their communities by maintaining a good balance between providing support but not creating dependency (Walsh et al., 2015).

One main source of support reported by SSPs as well as OTPs was the church, which often provided financial and emotional support as well as social interaction. Several South African studies have found that stroke survivors perceive their church as a source of support (Govender et al., 2019; Jongen et al., 2019). Rhoda *et al.* (2015) highlighted that for many African stroke survivors, leisure activities are associated with attending church and engaging in religious activities. Although, OTPs perceived that their stroke survivors did not really engage in leisure activities, acknowledging the need to attend previous religious activities is a way that occupational therapists could address leisure participating. Other forms of support perceived by both SSPs, and OTPs were the stroke support groups in the community. Likewise, in the Western Cape (Cawood & Visagie, 2015) as well as in Australia (Andrew et al., 2018), stroke support groups have also been highlighted as a factor that facilitates community reintegration.

Limited cultural factors were identified as facilitators, only one participant found that culturally he was expected to fulfil the role be in control of things at his home and therefore he did activities such as shopping and managing the finances.

Additional to the support received from their families and communities, SSPs perceived economic systems and support such as disability grants and *stokvels* as a facilitator to community reintegration. *Stokvels* refers to an informal self-help group of people that pool their funds together on a regular basis so that they can save money and then have a form of rent free loan they can access (Mduduzi & Khumalo, 2019). It is mainly used to save for unforeseen expenses or to fund small scale businesses (Mduduzi & Khumalo, 2019), and provides an opportunity for stroke survivors to supplement their meagre disability grants or to fund new ways of income generation.

Additional environmental facilitators perceived by SSPs, and OTPs were the supportive policies and systems at clinics that prioritised wheelchair users. The Community Orientated Primary Care approach implemented by the Western Cape DoH was also identified as a beneficial policy as it advocates for services to be provided in the community and allowed for OTPs to conduct home visits. The fact that OTPs identified this policy, is a positive indication of how current policies, strategies and programmes a specific focus on the primary levels of healthcare

are starting to be implemented. Occupational therapy participants also found the ability to work within an MDT, conduct home visits and the availability of midlevel healthcare providers as a facilitator to rendering community reintegration services. Although the South African guideline for managing ischemic stroke and transient ischemic attacks (Bryer et al., 2011) provides limited guidelines on rehabilitation services at PHC level, the Australian clinic guideline for stroke management emphasises (Australian National Stroke Foundation, 2010) that rehabilitation should be provided in the home and if there is multidisciplinary community rehabilitation and carer support services, early supported discharge can be considered.

Another system that both SSPs and OTPs identified as a facilitator was the availability of accessible transport. Examples included the stroke support group taxi that came to pick up SSPs at their homes and had a small step that made it easier to get in. Stroke survivor participants also mentioned using Uber as a way to travel alone. The use of Uber as a transport mode has not been mentioned in previous studies conducted in the Western Cape but is emerging as a possible asset that could be used to address the lack of accessible public transport. Unfortunately, it is still more expensive and would not be accessible to all stroke survivors.

The availability of external structure to hold onto when walking as well as less crowded area and even surfaces was also perceived as a facilitator to community reintegration. Occupational therapy participants also identified accessible homes and access to basic amenities made is easier for participants to be independent.

The last environmental facilitator identified was the availability to assistive technology. In contrast to having inappropriate devices or experiencing problems with the devices they had, SSPs perceived the availability of assistive devices as a facilitator to community reintegration. SSPs experienced that mobility assistive devices like walking sticks and wheelchairs assisted them in managing their fatigue and mobilising outside their homes. Occupational therapy participants also found that the availability of wheelchairs allowed SSPs to go out of the home and attend activities such as going to church. In confirmation, Algurén *et al*. (2012) argued that assistive devices specifically for indoor and outdoor mobility such as wheelchairs and walking frames are crucial for the health related QoL of stroke survivors.

5.4 CONCLUSION

This study revealed that stroke survivors living in the Eastern SD of the Western Cape, have similar experiences to community reintegration as well as similar barriers and facilitators to many other stroke survivors in the Western Cape, other parts of South Africa and internationally. Although occupational therapists experienced and perceived similar facilitators and barriers to facilitating community reintegration, they showed limited insights into cultural systems such as stokvels or the importance of religious activities as a form of leisure. The next chapter serves to highlight the main findings, limitations and strengths of this study as well provide recommendations for clinical practice and further research.

CHAPTER 6: CONCLUSION

6.1 INTRODUCTION

There were two research questions that guided this study:

- What are the experiences of stroke survivors regarding community reintegration in the Western Cape, 1 to 3 years after in-patient rehabilitation at WCRC?
- What are the perceived barriers and facilitators to community reintegration as perceived and experienced by the stroke survivors and community-based occupational therapists in the Eastern SD of the Western Cape?

This last chapter will answer these two research questions by summarising the findings that emerged from the three main themes described and discussed in chapter four and five. It will also describe the strengths and limitations identified in this study. Lastly it will provide recommendations for clinical practice and further research.

6.2 OVERVIEW OF THE STUDY

6.2.1 Main findings and themes that emerged

The first aim of the study was to explore how stroke survivors living in the Eastern SD of the Western Cape experience community reintegration after having received intensive in-patient rehabilitation at WCRC. In this study, the answer to this question emerged as the first theme, that described the changes SSPs experienced in occupational performance after their stroke.

The study highlighted that the levels of community reintegration achieved by stroke survivors remained limited, despite having received intensive in-patient rehabilitation for several weeks. Stroke survivor participants experienced occupational performance limitations in ADL participation, IADL participation, health management, leisure participation, social participation, and the ability to return to work. It is important to note that most of these participants reported not receiving further therapy after being discharged from in-patient therapy, often due to services not being available or not being referred. These findings were already highlighted 12 years ago by Rhoda *et al.* (2009) who found that stroke survivors who had received in-patient therapy did not receive continued rehabilitation in their communities and that the available community services at CHC's were not optimally organised. In agreement, this study

highlighted that the coordination of continued care is not optimal from the referring institutions as well as from the receiving community services.

In theme one, the occupational performance limitation in terms of ADLs included difficulties in completing selfcare tasks like bathing and shower independently as well as limitations with functional mobility inside and outside their homes. In the area of IADLs, difficulties were experienced in completing tasks like washing clothes, cleaning the house, washing dishes, gardening, managing the household finances and doing grocery shopping. These tasks were largely affected due to the loss of functional mobility inside and outside the house, a loss of endurance and poor bilateral upper limb integration. In the area of health management, occupational performance limitations included difficulty in remembering appointments and to taking medication, accessing continued rehabilitation services, and attending appointments at their nearest clinic. Stroke survivor participants also experienced challenges in accessing other services in the community such as obtaining a disability grant.

Occupational performance limitations in the areas of leisure participation included difficulty in engaging in tasks that require bilateral upper limb integration like playing guitar or other activities that required good mobility like dancing and going to live sport matches. Stroke survivor participants also experienced changes in their social participation. Many reported becoming more home bound and being dependent on people vising them in their homes. Engagement in social events outside the house also became difficult due to mobility and transport difficulties and SSPs became dependent on other to engage in these events. Although the lack of leisure participation has previously been found, this study highlighted that some OTPs did not actually incorporate this as an aspect in their treatment, which indicates some areas of community reintegration being neglected.

The consensus was that SSPs experienced less social interaction than prior to their stroke although one SSP reported an increase of visitors since he had his stroke. Lastly all SSPs found that they were unable to return to work after their stroke except one participant that was able to work again on a casual basis, and as a result all participants were dependent on social assistance

The second aim of the study was to explore what the barriers and facilitators to community reintegration are as perceived by the stroke survivors and community-based occupational

therapists in the Eastern SD of the Western Cape. In this study, the answer to this question emerged as the second and third theme.

The second theme that emerged was the barriers to community reintegration as perceived and experienced by the SSPs. This information was triangulated with the barriers to community reintegration as perceived and experienced by the community-based occupational therapist in the Eastern SD of the Western Cape. The barriers that were identified by SSPs and OTPs in this study were:

- Personal factor such as the loss of mobility, memory loss and speech deficits, a loss of motivation, the fear of falling, the severity of the initial stroke and if participants had experienced any recurrent strokes.
- Environmental factors such as inaccessible transport, uneven terrain, long travel distances and inaccessible structures in homes and public areas such as small spaces and stairs. Equally important was the lack of or excessive social support received, cultural barriers and the loss of finances. Lastly, participants reported the poor coordination of discharge and follow-up rehabilitation as well as barriers ascribed to having inappropriate or a lack of assistive devices.

The third and last theme that emerged was the facilitators to community reintegration as perceived and experienced by the SSPs. This information was triangulated with the facilitators to community reintegration as perceived and experienced by the community-based occupational therapist in the Eastern SD of the Western Cape. The facilitators that were identified by SSPs and OTPs in this study were:

- Personal factors such as having attended in-patient rehabilitation, as well as having a strong belief system and feeling motivated.

- Environmental factors included various support structures. For instance, the social support received from family and the community and supportive economic systems such as disability grants and stokvels were identified as facilitators to community reintegration. Furthermore, supportive polices and systems that prioritised persons with mobility restrictions and encouraged rehabilitation in persons homes improved service delivery that facilitated community reintegration. Participants also experienced having accessible

transport, external structures that assisted mobility and the availability of appropriate assistive devices as a facilitator.

Although many of the facilitators identified in this study have been reported in other studies, this study highlighted new community systems such as stokvels that have provided stroke survivors further opportunities to continue with income generation. This study has highlighted again the importance of taking into consideration the community resources when providing community reintegration services.

6.2.3 Strengths

Although this study had a small sample size with only 11 participants the data was saturated, and the findings were triangulated with the data that emerged from the OTPs which allowed the researcher to cross verify the results from more than one source and test the consistency of the findings.

The researcher's familiarity with the context also provided understanding and insight into the participant's responses and assisted the researcher with cuing during the interview process. Additionally, the researcher's employment at WCRC during the study period made it possible to access updated contact details for the participants, therefore increasing the the number of possible participants for the study.

Using a qualitative methodological approach to data collection provided the researcher the opportunity to explore the perceptions and lived experiences of the SSPs and OTPs. Thereby providing rich insights that would not have been obtained through a quantitative methodological study. Additionally, by using the PEOP model as a guideline for the codes and themes the researcher was able to present the results in a clear outline and to maintain a unique occupational therapy perspective on the data that emerged and during the discussion presented in this study.

6.2.4 Limitations

Several limitations arose during the study.

Firstly, member checking with SSPs was not possible due to practical limitations. Although researcher's codebook was reviewed by the supervisor to check for bias, the lack of member checking could limit confirmability to some extent.

Secondly, data collection took place during the COVID-19 pandemic which extended the data collection process and may have influenced the number of participants willing to take part in the study.

Thirdly, as interviews took place in participants native language some of the transcriptions were translated from Afrikaans and isiXhosa to English, therefore some nuances and depth of quotes used may have been lost in the translation process. In addition, the translator used for the isiXhosa interview was not a formally trained translator or trained in relation to data collection. Although both the participant's dialogue and the translator's dialogue were transcribed and translated by a qualified translator and transcriber, some discrepancies could be observed in how the participant understood some of the interview questions and the responses provided by the translator. Two other factors that were considered when analysing the data and interpreting the results were that not all participants were articulate and the presence of the researcher during the interview could have biased the responses given (Creswell, 2014).

Lastly, due to the small sample size of OTPs, the research aimed to explore the perceived barriers and facilitators to community reintegration as experienced by community-based occupational therapist could not be fully achieved and the data could only be used to triangulate the data that emerged from the SSPs.

6.3 RECOMMENDATIONS

6.3.1 Recommendations for clinical practice

From the study results several recommendations could be made. Firstly, to occupational therapist providing in-patient rehabilitation services and secondly occupational therapist providing rehabilitation services at community level.

Occupational therapists providing in-patient rehabilitation services should:

- Have a comprehensive discharge plan.
- On discharge, provide stroke survivors with a referral to the nearest occupational therapist with pre-determined follow-up appointment dates where possible. Contact should therefore be made with the community-based service providers to arrange the necessary follow-ups, equipment and support services (Andrew et al., 2018).

- Ensure that patients and caregivers are explained how to access these services including the date, time, and place. All discharge plans need to be documented, filed and a copy provided to the stroke survivor (Andrew et al., 2018) in the form of a referral letter and discharge report. Discharge reports should be comprehensive enough that effective continuation of treatment can take place.
- Make sure that adequate and comprehensive caregiver training with some practice opportunities takes place before discharge. Training should include the care and use of devices issued, adaptive methods that were learned during stroke survivor's in-patient admission and the importance of allowing stroke survivors to engage in previously meaningful activities. Discharge plans therefore need to be client specific and be made in consultation with the family, taking the stroke survivor and caregivers' level of literacy into account (Andrew et al., 2018).
- Provide preventative health education to the stroke survivors and their caregiver, regarding stroke and how reoccurrence and secondary complications can be prevented This should include risk factors and lifestyle changes that can prevent a second stroke (Andrew et al., 2018) as well as strategies to maintain and improve motivations so that stroke survivors have the intrinsic motivation to participate in activities, maintain a healthy lifestyle and reintegrate in their home and communities. Significant improvements in patient and carer knowledge have been reported through active versus passive provision of information (Forster et al., 2012) and therefore training should allow active participation through interaction and the asking of questions (Andrew et al., 2018).
- Understand the regulations and policies regarding service delivery at PHC level as per Healthcare 2030 Policy (Western Cape Government, 2014a) as well as the recommendations regarding supported discharge so that the necessary groundwork is completed prior to discharge.

These recommendations are in line with current literature that recommends a comprehensive discharge plan for stroke survivors, to facilitate adequate access to continued rehabilitation and support, in accordance with the CBR philosophy and ESD procedures (Forster et al., 2012; Andrew et al., 2018).

Occupational therapist providing rehabilitation services in the community should:

- Ensure that there are clear guidelines for administrative staff regarding booking systems. This would prevent stroke survivors going to the clinic to book appointments and being turned away when the therapist is not there.
- Advocate for stroke survivors when attending higher management meetings. This should include advocating for the training of CRWs that could assist with service delivery at community level or the provision of a bridging course that would provide current CHWs with the skills to assist with rehabilitation. Several South African studies have recommended an increased partnership between CHWs or CRWs and occupational therapist (Naidoo, Van Wyk & Joubert, 2016; Jejelaye, Maseko & Franzsen, 2019; Scheffler & Mash, 2019). Literature recommends that CHWs roles should be defined in terms of rehabilitation and their services broadened to include home-based stroke rehabilitation (Jejelaye, Maseko & Franzsen, 2019; Scheffler & Mash, 2020). In addition, CHW training should be more specific so that they can provide a service focussing mainly on training and supporting caregivers, providing recommendations on managing environmental barriers, enabling access to assistive devices and making the necessary referrals to health care services such as occupational therapy and physiotherapy (Scheffler & Mash, 2019).
- Keep meticulous statistics of the assistive devices required by stroke survivors so that this can be used to advocate for increased budget allocation for assistive technology that will aid occupational independence.
- Where possible provide services in the home and involve midlevel workers when conducting home visits (Naidoo, Van Wyk & Joubert, 2016). In doing so, stroke survivors can receive guidance on how to resume previous activities, access to community services as well as having the opportunity to practice activities at home with professional guidance (Walsh et al., 2015). The increased involvement of CHWs/CRWs could potentially save therapists the time taken to screen patients and could provide them better guidance in assisting patients with ADLs at home.
- Strengthen their relationships within PHCs, CHCs and community stakeholders such as churches, support groups, non-government, and non-profit organisations. In addition, other resources in their PHC facilities and community that can assist in facilitating the community reintegration of stroke survivors should be considered such as stokvels and community council meetings. The principles of CBR rely heavily on the need for

intersectoral collaboration and teamwork (Philpott, McLaren & Rule, 2020). It is thus crucial that an MDT approach is followed when planning occupational therapy services in the community. This includes working together not only with other rehabilitation healthcare practitioners but also with PHC nurses when planning clinic-based services and the content of patient and family education (Naidoo, Van Wyk & Joubert, 2016).

- As part of the collaboration with community stakeholders working together to formulate appropriate content for support groups to include topics such as managing family and friends' reaction to disability in social settings, self-acceptance after disability, facilitation of the grief process after an acquired disability as well as ensuring appropriate exercises and activities are planned.
- Together with an improved MDT approach, occupational therapists need to improve their collaboration with the communities that they service. Working closely with PwDs and community leaders will allow occupational therapists to identify the occupational injustices and social determinants of health in a specific community (Townsend & Wilcock, 2004; Naidoo, Van Wyk & Joubert, 2017). In doing so occupational therapists will be able to advocate for stroke survivors by highting the occupational rights of PwDs, provide person-centred services and play a stronger role in health promotion (Nilsson & Townsend, 2010; Naidoo, Van Wyk & Joubert, 2017). Subsequently appropriate and sustainable health programmes can be developed (Dookie & Singh, 2012; Naidoo, Van Wyk & Joubert, 2017).

Lastly, in accordance with previous studies conducted in the Western Cape (Gretschel, Visagie & Inglis, 2017), the loss of mobility has been highlighted as a major challenge post stroke and largely affecting community reintegration. It is therefore the responsibility of occupational therapists at all levels of care to optimise patients' independent mobility by providing assistive devices that facilitate indoor and outdoor mobility as well as providing options for accessible transportation (Algurén et al., 2012).

6.3.2 Recommendations for further research

Based on this study's finding, several recommendations for further research can be made.

Owing to the small sample size of occupational therapists servicing the Eastern SD of the Western Cape, future studies could expand on exploring the experiences of the occupational therapists in the larger metropole area. It would also be important to identify what the current

skills are of CRWs and CHWs and what areas of training they would need to expand their abilities in providing basic rehabilitation to stroke survivors in their homes.

The study highlighted the deficit of continued rehabilitation currently at the community level in the Eastern SD. Pilot studies that explore how more comprehensive services can be provided despite the lack of resources would be valuable in providing guidelines to occupational therapist on service delivery strategies that would allow more time for the provision of home-based interventions. This would require a comprehensive and critical in-depth exploration into the needs of stroke survivors in terms of continued rehabilitation in the community so that targeted services can be provided, since this study highlighted that some SSPs stopped attending therapy as they felt the therapy was not appropriate to their needs.

The study highlighted the stroke support groups were mostly seen as facilitators to community reintegration but sometimes were a barrier due to inappropriate information that was presented. Further research could explore the content of current stroke support groups to explore possible ways that other support groups can be introduced, or current services can be adjusted to address more areas of community reintegration.

The study also highlighted the limited time that occupational therapists spend on providing occupational-based intervention in the community. Further research could explore the extended role of occupational therapists in the community in facilitating community reintegration with a focus on occupations and advocacy activities that occupational therapists can engage in at community level.

Lastly, further studies can explore alternative employment opportunities in the area while considering current practices in the community such as stokvels, that could be used to finance small business opportunities.

6.4 CONCLUSION

This chapter summarised the whole study by providing an overview of the main findings and the themes that emerged as well as identifying the strengths and limitations of the study. Lastly, recommendations were given for clinical practice as well as further proposed research.

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APPENDIX A: REHABILITATION OUTCOME LEVELS

(Landrum, Schmidt & McLean, 1995)

Outcome Level	Description	Level of Care
Level 0: Physiological Instability	The patient's acute medical diagnostics has not yet been managed and the patient presents as with the onset of his/her illness or injury.	Acute hospital, often in ICU
Level I: Physiological Stability	Patient has been medically and physiologically diagnosed and a treatment plan is established. All the main medical complications have been resolved and the patient can be discharge from the acute hospital.	Acute Hospital
Level II: Physiological Maintenance	All basic rehabilitation outcomes that are needed to for long-term physiological health are achieved. Strategies to prevent secondary complications have been established such as safe feeding, prevention of aspiration, bowl and bladder management and pressure sore prevention. Functional goals are limited to that what is needed for physiological maintenance such as basic bed mobility and transfers in his/her capacity.	Hospital-based acute rehabilitation centres.
Level III: Residential Reintegration	An acceptable level of independent functioning for his home/ long-term residence environment is achieved. The patient is functional in his/her self-care, mobility, general communication, and home care. The family / carer may play a role in achieving these functions where needed. Patient is safe to be discharged to their home.	Post-acute rehabilitation centre
Level IV: Community Reintegration	An acceptable level of functioning within the patient's community is achieved. The patient can mobilise safely in his/her community, manage finances, monitor his/ her own health, and participate in community and recreational activities.	Community-based services and support groups
Level V: Productive Activity	The patient can participate in productive activities within his or her capabilities. He/ She can now engage in educational, vocational, or avocational pursuits. Often work visits, education of the employer, education in specific vocations and job hardening needs to be done by the therapy team.	Community-based services or vocational rehab centre.

APPENDIX B: STROKE PARTICIPANT DATA SATURATION TABLES

Theme 1: Changes experienced in occupational performance

Data Saturation Table			Participant	1	2	3	4	6	7	8	9	10	11	12	Frequency
Theme 1	**Categories**	**Sub-categories**	**Codes**												
Changes experienced in occupational performance	Changes due to Personal Factors	Physiological Changes	Limited occupational performance due to a loss of endurance and strength	√	√	√		√	√	√	√	√	√		9
		Neuro-behavioural Subsystem Changes	Changes in occupational performance inside and outside home due to a loss of mobility	√	√	√	√		√	√	√	√	√	√	10
		Cognitive Changes	Increased dependence on family and friend's due residual cognitive changes				√		√		√	√			4
		Spiritual Changes	Questioning belief system and disappointment in spiritual support vs finding strength in it						√	√		√			3
		Psychological Changes	Feelings of frustration, bitterness, disappointment, shame	√					√	√	√		√		5
			Difficulty to accept loss of function and worry about future	√	√	√	√	√	√	√	√	√	√	√	11
			Resigned to fate	√		√			√	√	√		√		6
	Changes due to Environmental Factors	Social Support	Decreased social involvement of family and friends				√		√	√					3
			Positive of support given by family and community		√		√	√	√	√	√	√	√		8
		Social and Economic Policies	Dependence on others for community mobility	√	√	√	√	√	√	√	√	√	√	√	11
		Cultural Values and Beliefs	Changes in attitudes from community and family								√				1
		Physical and Natural Environment	Inaccessible structural layouts in homes & community restricting mobility, homecare, selfcare and leisure			√			√				√		3
			Inaccessible natural environment restricting home and community mobility	√		√			√	√	√				5
	Changes within Occupations and Performance	Changes in structure of activities	Limited leisure participation and socialising being limited to the home	√	√	√	√		√	√	√	√	√	√	10
			Inability to generate an income and dependence on a social grant	√	√	√	√	√		√		√	√	√	9
			Need to adjust how tasks are completed	√	√	√		√	√	√		√	√	√	9
		Changes in roles	Loss of the role of breadwinner		√								√		2

			Loss of the role of helper/ carer/ and being an authority figure				√			√			√	√	4
			Reassignment of homecare role s	√			√		√		√			√	5

Theme 2: Barriers to community integration

Data Saturation Table			**Participant**	**1**	**2**	**3**	**4**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**Frequency**
Theme 2	**Categories**	**Sub-categories**	**Codes**												
Barriers to community integration	Personal factors	Physiological Barriers	Loss of physical strength and endurance	√	√	√	√	√		√	√	√	√	√	10
		Neuro-behavioural Subsystem Barriers	Loss of mobility and visual impairments	√	√	√	√				√	√	√	√	8
		Cognitive Barriers	Memory loss and forgetfulness		√			√	√		√				4
			Speech impairments				√				√				2
		Psychological Barriers	Uncertainty about abilities and fear of falling						√	√			√		3
			Loss of motivation	√					√	√	√		√	√	6
	Environmental Factors	Social Support Barriers	A lack of or excessive social support from family	√			√		√	√					4
		Social and Economic Systems and Policy Barriers	Inaccessible transport						√		√			√	3
			Poor medical policies surrounding the coordination of rehab and discharge services			√		√		√	√		√		5
			Poor policies regarding service users with mobility limitations			√		√	√						3
			Economic factor like the loss of finances	√	√	√	√			√			√		6
			COVID-19 pandemic restrictions		√		√	√	√	√	√		√		7
		Cultural Barriers	Cultural and personal values such as such as not wanting help and fearing the communities' attitude					√		√	√			√	4
		Physical and Natural Environmental Barriers	Built environmental factors like stairs and small spaces	√		√			√	√		√			5
			Natural environmental factors like uneven terrain and long travel distances	√		√	√		√	√	√			√	7
		Assistive Technological Barriers	Inappropriate devices/ problems with devices					√	√						2
	Occupational &Performance Factors	Tasks	Heavy weights		√										1
			Tight clothing								√				1

Theme 3: Facilitators to community integration

Data Saturation Table			Participant	1	2	3	4	6	7	8	9	10	11	12	Frequency
Theme 3	**Categories**	**Sub-categories**	**Codes**												
Facilitators to community integration	Personal factors	Neuro-behavioural Subsystem Facilitators	Having attended in-patient rehabilitation		√	√	√	√	√	√	√	√	√	√	10
			Having had a mild stroke and a fast improvement in gait		√	√									2
			Independent mobility		√	√	√	√			√			√	6
		Psychological Facilitators	Physiological factors like motivation and drive		√		√	√				√			4
		Spirituality	Belief System		√	√	√								3
	Environmental Factors	Social Support Facilitators	Decreased social support						√					√	2
			Social support from the family and community	√	√	√	√	√	√	√	√	√	√	√	11
		Social and Economic Systems and Policy Facilitators	Accessible/ alternative public transport				√		√		√			√	4
			Social welfare systems and policies		√	√		√	√	√	√	√	√	√	9
			External motivators such as dependants		√	√						√			3
			Supportive policies and systems e.g., medical systems, stroke support groups	√	√			√	√	√	√	√	√	√	10
		Cultural Facilitators	Cultural expectations of role fulfilment					√							1
		Physical and Natural Environmental Facilitators	External structures to hold on to				√		√	√			√		4
			Less crowded areas and even surfaces			√				√	√	√			4
		Assistive Technological Facilitators	The availability of assistive devices	√	√	√	√	√	√	√	√	√	√		10

APPENDIX C: HUMAN RESEARCH ETHICS COMMITTEE APPROVAL

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

2021/03/19

Ms HC Lindner
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

Sent by e-mail to: celicelindner@gmail.com

Dear Ms Lindner

Re: **Protocol Ref No:** M190530
Protocol Title: *Experiences and perceptions of stroke survivors and occupational therapists on community reintegration post stroke in the Western Cape*
Principal Investigator: Ms HC Lindner

Thank you for your e-mail of 2021/03/11.

I confirm that we have noted and approve of your proposal to revert to the original study protocol and title, due to circumstances beyond your control. I have attached a revised Clearance Certificate to reflect the reversion to the *status quo ante*.

Thank you for keeping us informed.

Yours Sincerely

.....
Mr I Burns
For the Human Research Ethics Committee (Medical)

.....
Dr CB Penny, Chairperson, Human Research Ethics Committee (Medical)

APPENDIX D: WESTERN CAPE DEPARTMENT OF HEALTH ETHICS APPROVAL

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 0466; fax: +27 21 483 4068
9th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_202001_005
ENQUIRIES: Dr Sabela Petros

1 Jan Smuts Ave
Johannesburg
2000

For attention: Mrs Hendrina Lindner

Re: Experiences and perceptions of stroke survivors and occupational therapist on community reintegration post stoke in the Western Cape.

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:

Kleinvlei CDC	**Mr Thulile Mtubisi**	**021 904 4410**

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 INTELLIGENCE
DATE:
CC

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
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5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_202001_005
ENQUIRIES: Dr Sabela Petros

1 Jan Smuts Ave
Johannesburg
2000

For attention: Mrs Hendrina Lindner

Re: Experiences and perceptions of stroke survivors and occupational therapist on community reintegration post stoke in the Western Cape.

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:

Macassar CDC	**Moses Witbooi**	**021 360 4386**

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.
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Yours sincerely

DR M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 15/12/2020
CC

Western Cape Government
Health

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www.capegatewav.gov.za

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

Nomzamo CDC	**Ndabazabo Maliso**	**074 199 8834**

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.
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4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE:
CC

Dr Melvin Moodley
Director: Health Impact Assessment
23 FEB 2021

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

Western Cape Rehab Centre	**Hans Human**	**021 370 2316**

Kindly ensure that the following are adhered to:

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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).
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4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 17/4/2020
CC

APPENDIX E: STROKE PARTICIPANT DEMOGRAPHIC INFORMATION

Date: _____

Place: _____

Interviewer: HC Lindner

Number allocation: _____

Instructions for the interviewer: Introduction of the interviewer, explain the purpose of the research, explain how the participants were selected, reinforce that it is voluntary participation and explain how the interview will proceed. Inform participant that where multiple categories are given, only one option must be indicated, unless otherwise indicated.

<table>
<tr><th colspan="2">Personal Information</th></tr>
<tr><td>How old are you?
_____</td><td>Please specify your gender.
_____</td></tr>
<tr><td>What is your marital status?
○ Married
○ Widowed
○ Divorced
○ Separated
○ Never married
○ Other, (please specify)
_____</td><td>Whom do you live with?
○ Alone
○ With partner
○ With children
○ With family
○ With friends
○ Other, (please specify)
_____</td></tr>
<tr><td colspan="2">What is the highest level of education that you have completed?
○ Less than high school degree
○ High School or equivalent
○ Diploma
○ Bachelor’s degree</td></tr>
<tr><th colspan="2">Employment information</th></tr>
<tr><td>Describe your current state of employment
○ Employed on contract basis
○ Employed permanently
○ Casual worker
○ Unemployed, looking for work
○ Unemployed, not looking for work
○ Retired
○ Disabled, unable to work
○ Other, (please specify)
_____</td><td>Describe your state of employment in the year prior to your stroke
○ Employed on contract basis
○ Employed permanently
○ Casual worker
○ Unemployed, looking for work
○ Unemployed, not looking for work
○ Retired
○ Disabled, unable to work
○ Other, (please specify)
_____</td></tr>
</table>

Do you currently receive a Disability Grant? ○ Yes ○ No	
Medical information	
How many strokes have you had? ○ 1 ○ 2 ○ 3 ○ More	When was your last stroke? ○ 1 year ago ○ 2 years ago ○ 5 years ago ○ Longer
How long were you admitted to a hospital, after your stroke? ○ > one week ○ > two weeks ○ > one month ○ Longer, (please specify) _____	How long were you admitted to Western Cape Rehabilitation Centre? ○ >3 weeks ○ >6 weeks ○ > 8 weeks ○ > 12 weeks ○ Longer, (please specify) _____
For how long were you away from your home from the day of your first admission, until your return home, after your last stroke? o > 1 month o >3 months o >6 months o > 9 months Longer, (please specify) _____	

DEMOGRAFIESE VRAELYS VIR BEROERTE DEELNEMER

Datum: _____

Plek: _____

Onderhoudvoerder: HC Lindner

Toegekende getal: _____

Instruksies vir die onderhoudvoerder: Stel die onderhoudvoerder bekend, verduidelik die doel van die navorsing, verduidelik hoe die deelnemers gekies is, beklemtoon dat deelname vrywillig is en verduidelik hoe die onderhoud gaan verloop. Stel die deelnemer daarvan in kennis dat, as daar verskillende kategorieë gegee word, slegs een opsie aangedui moet word tensy anders aangedui.

<table>
<tr><th colspan="2">Persoonlike Inligting</th></tr>
<tr><td>Hoe oud is u? _____</td><td>Wat is u geslag? _____</td></tr>
<tr><td>Wat is u huwelikstatus?
o Getroud
o Weduwee
o Geskei
o Vervreemd
o Nooit getroud
o Ander, (wees spesifiek)
_____</td><td>Met wie woon u?
o Alleen
o Met ‘n eggenoot
o Met u kinders
o Met familie
o Met vriende
o Ander, (wees spesifiek)
_____</td></tr>
<tr><td colspan="2">Wat is die hoogste vlak van opleiding wat u voltooi het?
o Minder as ‘n hoërskool graad
o Hoërskool of die ekwivalent
o Diploma
o Baccalaureus graad</td></tr>
<tr><th colspan="2">Werks Inligting</th></tr>
<tr><td>Beskryf u huidige diensstaat.
o Op kontrak in diens geneem
o Permanent in diens geneem
o Informele werker
o Werkloos, opsoek na werk
o Werkloos, nie opsoek na werk nie
o Afgetree
o Gestremd, kan nie werk nie
o Ander, (wees spesifiek)
_____</td><td>Beskryf u diensstaat in die jaar voor u beroerte?
o Op kontrak in diens geneem
o Permanent in diens geneem
o Informele werker
o Werkloos, opsoek na werk
o Werkloos, nie opsoek na werk nie
o Afgetree
o Gestremd, kan nie werk nie
o Ander, (wees spesifiek)
_____</td></tr>
</table>

Ontvang u ‘n ongeskiktheid toelaag?
- Ja
- Nee

Mediese Inligting

Hoeveel beroertes het u al gehad? - 1 - 2 - 3 - Meer	Wanneer het u, u beroerte gehad? - 1 jaar terug - 2 jaar terug - 5 jaar terug - Langer terug
Vir hoe lank was u in hospitaal opgeneem na u beroerte? - > een week - > twee weke - > een maand - Langer (wees spesifiek) _____	Hoe lank was u by WCRC opgeneem? - >3 weke - >6 weke - > 8 weke - > 12 weke - Langer (wees spesifiek) _____

Vir hoe lank was u van u huis af weg van u eerste opname tot na die tyd, met u laaste beroerte?
- o > 1 maand
- o >3 maande
- o >6 maande
- o > 9 maande
- Langer, (wees spesifiek) _____

APPENDIX F: OCCUPATIONAL THERAPIST DEMOGRAPHIC QUESTIONNAIRE

Date: _____

Place: _____

Interviewer: HC Lindner

Number allocation: _____

Instructions for the interviewee: These questions pertain to the period that you have been employed at your clinic/s and serves to provide background information for the interview to be conducted. Where multiple categories are given, only one option must be indicated, unless otherwise requested. Should anything be unclear, please feel free to ask.

Personal Information	
How old are you? _____	Please specify your gender. _____
How long have you been working at this clinic? ○ >1 year ○ >5 years ○ > 10 years ○ Longer (please specify) _____	What was your most recent occupation prior to your current employment? ○ Student ○ Community service OT ○ OT working in private ○ OT working in Department of Health ○ Other (please specify) _____
In what province did you work prior to your current employment? ○ Western Cape ○ Eastern Cape ○ Northern Cape ○ Free state ○ Gauteng ○ Limpopo ○ Kwazulu-Natal ○ Mpumalanga ○ North West	At what level of care did you work prior to your current employment? ○ Primary health care ○ Secondary health care ○ Tertiary health care ○ NGO/NPO ○ Private ○ Other, (please specify) _____

Please indicate any specific areas of interest below.

- Paediatrics
- Neurology
- Psychiatry
- Orthopaedics
- Hands
- Other, (please specify) _____

Stroke Patient Related Information

How regularly do you see stroke patients?

- Daily
- Weekly
- Monthly
- Never
- Other, (please specify) _____

On average what percentage of your patients are stroke survivors?

_____

Please indicate an estimated percentage of stroke patients referred to you according to these stages of recovery.

Hyperacute (first 6 hours)

_____

Acute (day 1-two weeks)

_____

Sub-acute (three weeks- 6 months)

_____

Chronic (7 months and onward)

_____

Please indicate what specific stroke services you render. (Please indicate all that are applicable.)

- Individual
- Exercise Group
- Support Group
- UL Group
- ADL Group
- Home Visits
- Other, (please specify) _____

Where do you render these above-named services? (Please indicate all that are applicable.)

- Clinic
- Home

Other, (please specify)

_____

DEMOGRAFIESE VRAELYS VIR ARBEIDSTERAPEUT

DEELNEMER

Datum: _____

Plek: _____

Onderhoudvoerder: HC Lindner

Toegekende getal: _____

Instruksies vir die deelnemer: Hierdie vrae het betrekking op die tydperk wat u by hierdie kliniek werksaam is, en dien as agtergrondsinligting vir die onderhoud wat gevoer gaan word. Waar verskeie kategorieë voorsien word, moet slegs een opsie aangedui word, tensy anders versoek. Vra gerus indien daar enige onduidelikheid is.

Persoonlike Inligting	
Hoe oud is u? _____	Dui asseblief u geslag aan? _____
Hoe lank werk u al by hierdie kliniek? ○ >1 jaar ○ >5 jaar ○ >10 jaar ○ Langer (wees asseblief spesifiek) _____	Wat was u mees onlangse beroep voor u huidige werk? ○ Student ○ Diensjaar ○ AT in privaat ○ AT vir die Departement van ○ Gesondheid ○ Ander (wees asseblief spesifiek) _____
In watter provinsie het u gewerk voor u huidige werk? ○ Wes-Kaap ○ Oos-Kaap ○ Noord-Kaap ○ Vrystaat ○ Gauteng ○ Limpopo ○ KwaZulu-Natal ○ Mpumalanga ○ Noord-Wes	Op watter vlak van sorg het u gewerk voor u huidige werk? ○ Primêre gesondheidsorg ○ Sekondêre gesondheidsorg ○ Tersiêre gesondheidsorg ○ NGO/NPO ○ Privaat ○ Ander, (wees asseblief spesifiek) _____

Dui asseblief enige spesifieke areas van belangstelling aan?

- Pediatrie
- Neurologie
- Psigiatrie
- Ortopedie
- Hande
- Ander, (wees asseblief spesifiek) _____

Beroerte Pasiënt Verwante Inligting

Hoe gereeld sien u beroerte pasiënte?

- Daagliks
- Weekliks
- Maandeliks
- Nooit
- Ander, (wees asseblief spesifiek) _____

Watter persentasie van u pasiënte is gemiddeld beroerte oorlewendes?

_____

Dui asseblief aan ’n gemiddelde persentasie van beroerte pasiënte wat na jou verwys word volgend die volgende stadiums van herstel.

Hiperakuut (eerste 6 ure) _____

Akuut (dag 1-2 weke) _____

Sub-akuut (3 weke- 6 maande) _____

Kroniese (7 maande en verder) _____

Dui asseblief aan, enige beroerte verwate dienste wat u lewer. (Dui asseblief alle toepaslike moontlikhede aan.)

- Individueel
- Oefen Groep
- Ondersteunings Groep
- BL Groep
- ADL Groep
- Tuis-besoeke
- Ander, (wees asseblief spesifiek) _____

Waar lewer u hierdie bogenoemde dienste? (Dui asseblief alle toepaslike moontlikhede.)

- Kliniek
- Tuis
- Ander, (wees asseblief spesifiek) _____

APPENDIX G: STROKE PARTICIPANT INTERVIEW GUIDELINE

Date: _____

Place: _____

Interviewer: HC Lindner

Number allocation: _____

Instructions for the interviewer: Introduction of the interviewer, explain the purpose of the research, explain how the participants were selected, reinforce that it is voluntary participation and explain how the interview will proceed.

	NOTES
Question 1: Could you describe what activities you participated in before your stroke? Prompts: ○ activities that you participated in your home (*e.g.,* cooking, cleaning. gardening *etc*.) ○ activities that you participated in your community (*e.g*., attending church, playing sport, night watch etc) ○ activities that you really enjoyed prior to your stroke	

Question 2: Please describe how you have experienced being back in your home and in your community after your stroke. <u>Prompts:</u> ○ participation in previous activities (e.g., attending church, going shopping, accessing public transport) ○ emotional experience being back home ○ emotional experience being back in your community ○ activities at home that you really enjoy or find meaningful ○ activities in community that you really enjoy or find meaningful	

Question 3: What are the activities that you find difficult to do since you have returned to your home and community and why do you find it challenging? <u>Prompts:</u> ○ do you experience needing help in terms of physical tasks (*e.g.,* cleaning, gardening, *etc*.)? ○ do you experience needing help with getting around (*e.g.,* going to the clinic *etc.)?* ○ do you experience needing help with cognitive tasks (*e.g.,* doing subtractions *etc*.)? ○ do you experience challenges in participating in activities that you were able to do alone before? ○ do you experience challenges in participating in social events/ or being social? ○ do you experience challenges in terms of managing your finances since your stroke	

Question 4: What have you found to have helped you in returning to your home and community after this stroke? <u>Prompts:</u> ○ family ○ medical Care ○ church ○ accessible physical environment ○ assistive devices ○ positive attitudes of people ○ systems at the clinic ○ policies (*e.g.*, disability grant)	

Question 5: Looking back at your rehabilitation at Western Cape Rehabilitation Centre, what did you find to be the <u>most</u> helpful when you returned to your home and community?	
Question 6: Looking back at your rehabilitation at WCRC, what did you find to be the <u>least</u> helpful when you returned to your home/ community?	

Question 7: Have you attended any further rehabilitative services at your nearest clinic? • Yes- how have you experienced this? • No- why not?	

Mr/ Mrs_____, thank you so much for your willingness to participate in this interview and for the insightful information that you have shared.

Should any of this information need to be clarified at a later stage, I will be in contact. If at a later stage feel that you do not want to have the information you provided to be included in the research, you are more than welcome to contact me on the number provided. I would like to assure you again that this information will remain confidential and only myself, a transcriber and my supervisor will have access to it and your name will be excluded from the information sheet.[1]

[1] **Resources used for completing questionnaire:**

- Interview Format: Interview Protocol (Creswell, 2014).
- Prompts for Question 1& 4: Questions from the CHART assessment tool that measures societal participation for people with disabilities (Corrigan & Bogner, 2004) as well as challenges experienced according to a study conducted by Gretschel, Visagie and Inglis (2017).
- Prompts for Question 4: WHO definition of facilitators (Organisation, 2001)

ONDERHOUD RIGLYN VIR BEROERTE DEELNEMER

Datum: _____

Plek: _____

Onderhoudvoerder: HC Lindner

Toegekende getal: _____

Instruksies vir die onderhoudvoerder: Stel die onderhoudvoerder bekend, verduidelik die doel van die navorsing, verduidelik hoe die deelnemers gekies is, beklemtoon dat deelname vrywillig is en verduidelik hoe die onderhoud gaan verloop.

	NOTES
Vraag 1: Beskryf asseblief aand aan waste aktiwiteite u deel geneem het voor u 'n beroerte gehad het? <u>Leidrade:</u> ○ aktiwiteite waaraan u voorheen deelgeneem het in u huis (*bv*. kook, skoonmaak, tuinmaak *ens.*) ○ aktiwiteite waaraan u voorheen deelgeneem het in u gemeenskap (*bv.* kerk bywoon, sport deelname, buurtwag deelname *ens*.) ○ aktiwiteite wat u rêrig geniet om aan deel te neem voor u beroerte	

Vraag 2: Beskryf asseblief hoe u dit ervaar het om weer by die huis en in u gemeenskap terug te wees, na u beroerte. <u>Leidrade:</u> ○ deelname aan aktiwiteit wat u voorheen aan deelgeneem het (*bv.* kerk toe gaan, inkopies doen, publieke vervoer gebruik) ○ emosionele ervaring van terug by die huis wees ○ emosionele ervaring van terug in u gemeenskap te wees ○ deelname aan aktiwiteite in u huis wat u baie geniet of betekenisvol vind ○ deelname aan aktiwiteite in u gemeenskap wat u baie geniet of betekenisvol vind	

Vraag 3: Wat is die dinge wat u moeilik vind om te doen vandat u na u huis en gemeenskap teruggekeer het, en waarom vind u dit uitdagend? <u>Leidrade:</u> ○ vind u dat u hulp nodig het in terme van fisiese aktiwiteite (*bv.* skoonmaak, tuinmaak, *ens.)* ○ ervaar u dat u hulp nodig het met rond beweeg (*bv.* kliniek toe te gaan *ens.)* ○ ervaar u dat u hulp nodig het met aspekte soos u geheue (*bv*. wiskundige somme te doen *ens*.) ○ ervaar u enige uitdagings om deel te neem in dinge wat u voorheen alleen kon doen ○ ervaar u enige uitdagings daarin om deel te neem aan sosiale gebeurtenisse of om sosiaal te verkeer ○ ervaar u enige uitdagings in terme van finansies in vergelyk met voor u beroerte	

Vraag 4: Wat het u ervaar wat vir u deur hierdie hele proses, van terugkeur na u huis en gemeenskap , baie gehelp? <u>Leidrade:</u> ○ familie ○ mediese Sorg ○ kerk ○ ŉ toeganklike fisiese omgewing ○ hulpmiddels ○ die positiewe houding van mense ○ sisteme by die kliniek ○ beleide (*bv*. ongeskiktheidstoelaag)	

Vraag 5: As u terugkyk na u rehabilitasies by Wes-Kaapse Rehabilitasiesentrum, wat het u die <u>mees</u> nuttig gevind vir wanneer u terug gekeer het na u huis en gemeenskap toe?	
Vraag 6: As u terugkyk na u rehabilitasies by Wes-Kaapse Rehabilitasiesentrum, wat het u die <u>minste</u> nuttig gevind vir wanneer u terug gekeer het na u huis en gemeenskap?	

Vraag 7: Het u al enige verdere rehabilitasie dienste ontvang by u naaste kliniek? • Ja- hoe het u dit ervaar? • Nee- hoekom nie?	

Mnr/ Mev _____, baie dankie vir jou bereidwilligheid om deel te neem aan hierdie onderhoud en vir die insiggewende inligting wat jy gedeel het. Dit was baie gaaf van jou om die tyd af te staan om hierdie vrae te beantwoord.

Ek sal weer met jou in aanraking kom indien dit nodig sou wees om die inligting weer saam na te gaan nadat dit gewysig en deurwerk is. As jy op 'n later stadium voel dat jy nie die inligting wat jy verskaf het by die navorsing wil insluit nie, is jy welkom om met my kontak te maak. Ongelukkig sal ek jou nie as 'n deelnemer kan verwyder nie, maar die inligting sal nie weergee word nie. Jy kan my telefonies kontak met die nommer wat aan jou verskaf is. Ek wil vir jou net verseker dat hierdie inligting vertroulik sal bly en slegs ek, 'n transkribeerder en my toesighouer sal toegang daartoe hê en jou naam sal uitgesluit word van die inligtingsblad.[2]

[2] **Bronnelys:**

- Onderhoud Formaat: Interview Protocol (Creswell, 2014).
- Leidrade vir Vraag 1 & 4: Vrae van die CHART assesseringsinstrument wat sosiale deelname van mense met gestremdhede meet (Corrigan & Bogner, 2004) as ook uitdagings ervaar volgens 'n studie deur Gretschel, Visagie en Inglis (2017).
- Leidrade vir Vraag 4: WHO definisie van fasiliteerders (Organisation, 2001).

APPENDIX H: OCCUPATIONAL THERAPY PARTICIPANT INTERVIEW GUIDELINE

Date: _____

Place: _____

Interviewer: HC Lindner

Number allocation: _____

Instructions for the interviewer: Introduction of the interviewer, explain the purpose of the research, explain how the participants were selected, reinforce that it is voluntary participation and explain how the interview will proceed.

	NOTES
Question 1: What is your experience regarding stroke patients' re-integration to their respective communities? Prompts: o their participation at home (*e.g.,* cooking, cleaning, gardening, *etc.*) o their participation in their communities (*e.g.,* attending church, playing sport, involvement in a night watch *etc.*) o their participation in social activities (*e.g.,* social events or leisure activities) o their need for help in terms of physical tasks o their level of assistance needed considering any cognitive fallouts o their mobility needs o changes in their independence o changes in their financial circumstances and needs	

Question 2: Have you experienced any challenges in facilitating community re-integration of your stroke patients? <u>Prompts:</u> ○ any patient specific factors (*e.g.,* physical and cognitive functioning, mobility skills, patients' attitude, family support, other support structures such as church) ○ any environmental factors (*e.g.,* the accessibility of the physical environment, assistive devices, positive attitudes of people, community support ○ policies within clinic or larger area of service? (*e.g.,* disability grants, policies, medical care)	

Question 3: What factors have you found facilitate a patient's ability to re-integrate into their community? <u>Prompts:</u> ○ support network (*e.g.,* family, church, positive attitudes of people *etc.*) ○ environmental circumstances (*e.g.,* medical access, accessible physical environment) ○ available resources (*e.g.,* assistive devices) ○ specific systems or policies at the clinic (*e.g.,* waiting times, disability grant accessibility)	

Question 4: What factors have you found are barriers to a patient's ability to re-integrate into their community? <u>Prompts:</u> o marginalisation or exclusion (*e.g.,* family, church, attitudes of community *etc.*) o environmental circumstances (*e.g.,* medical access, physical environment) o available resources (*e.g.,* assistive devices, medical access) o specific systems or policies at the clinic (*e.g.,* waiting times, disability grant accessibility)	

Mr/ Mrs_____, thank you so much for your willingness to participate in this interview and for the insightful information that you have shared.

Should any of this information need to be clarified at a later stage, I will be in contact. If at a later stage feel that you do not want to have the information you provided to be included in the research, you are more than welcome to contact me on the number provided. I would like to assure you again that this information will remain confidential and only myself, a transcriber and my supervisor will have access to it and your name will be excluded from the information sheet.[3]

[3] **Resources used for completing questionnaire:**

- Interview Format: Interview Protocol (Creswell, 2014).
- Prompts for Question 4: Questions from the CHART assessment tool that measures societal participation for people with disabilities (Corrigan & Bogner, 2004) as well as challenges experienced according to a study conducted by Gretschel, Visagie and Inglis (2017).
- Prompts for Question 3: WHO definition of facilitators (Organisation, 2001)

ONDERHOUD RIGLYN VIR ARBEIDSTERAPEUT DEELNEMER

Datum: _____

Plek: _____

Onderhoudvoerder: HC Lindner

Toegekende getal: _____

Instruksies vir die onderhoudvoerder: Stel die onderhoudvoerder bekend, verduidelik die doel van die navorsing, verduidelik hoe die deelnemers gekies is, beklemtoon dat deelname vrywillig is en verduidelik hoe die onderhoud gaan verloop.

	NOTES
Vraag 1: Wat is jou ervaring met betrekking tot die herintegrasie van beroerte pasiënte in hulle gemeenskappe? <u>Leidrade:</u> o hulle deelname in die huis (*bv.* kosmaak, skoonmaak, tuinmaak *ens.*) o hulle deelname in hulle gemeenskappe (*bv.* kerk bywoning, deelname aan sport, deelname aan die buurtwag *ens.*) o hulle deelname aan sosiale aktiwiteite (*bv.* sosiale gebeurtenisse of deelname aan ontspannings aktiwiteite) o hulle behoeftes aan hulp met die uitvoering van fisiese take o hulle behoeftes aan hulp ten opsigte van kognitiewe uitvalle o hulle behoeftes aan hulp met mobiliteit o veranderinge ten opsigte van hulle onafhanklikheid o veranderinge ten opsigte van hulle finansiële toestand en behoeftes	

Vraag 2: Het jy al enige uitdagings ervaar om gemeenskap herintegrasie te fasilitering vir jou beroerte pasiënte? <u>Leidrade:</u> ○ enige persoonlike faktore van die pasiënte? (*bv.* fisiese en kognitiewe funksionering, mobiliteit vaardighede, pasiënte se houding, familie ondersteuning, ander ondersteunings strukture soos kerk) ○ enige omgewingsfaktore? (*bv.* toeganklikheid van die fisiese omgewing, hulpmiddels, positiewe houdings van ander menses, gemeenskap ondersteuning) ○ beleide binne die kliniek of groter diensarea? (*bv*. ongeskiktheidtoelaag, beleide, mediese sorg)	

Vraag 3: Watter faktore het jy ondervind, fasiliteer ’n pasiënt se vermoë om weer in sy/haar gemeenskappe te herintegreer? <u>Leidrade:</u> ○ Ondersteunings netwerk (*bv.* familie, kerk, positiewe houdings van ander mense ens) ○ Omgewingstoestande (*bv.* mediese toeganklikheid, toeganklikheid van die fisiese omgewing) ○ Beskikbare hulpbronne (*bv.* hulpmiddels) ○ Spesifieke sisteme of beleide in die kliniek (*bv.* wagtye, ongeskiktheidtoelaag toeganklikheid)	

Vraag 4: Watter faktore het jy ondervind as hindernisse tot ’n pasiënt se vermoë om weer in sy/haar gemeenskappe te herintegreer? Leidrade: o marginalisering of uitsluiting (*bv.* deur familie, kerke, die gemeenskap se houding *ens.*) o Omgewingstoestande (*bv.* mediese toeganklikheid, fisiese omgewing) o Beskikbare hulpbronne (*bv.* hulpmiddels, mediese toegang) o Spesifieke sisteme of beleide in die kliniek (*bv.* wagtye, ongeskiktheidtoelaag toeganklikheid)	

Mnr./ Mev._____, baie dankie vir u bereidwilligheid om deel te neem aan hierdie onderhoud en vir die insiggewende inligting wat jy gedeel het.

Indien enige van hierdie inligting of ’n latere stadium uitgeklaar moet word, sal ek u kontak. As u op ’n later stadium voel dat u nie die verskafde inligting by die navorsing wil insluit nie, is u welkom om my te kontak met die voorsiende telefoon nommer. Ek wil vir u net verseker dat hierdie inligting vertroulik sal bly en slegs ek, ’n transkribeerder en my toesighouer sal toegang daartoe hê en u naam sal uitgesluit word van die inligtingsblad.[4]

[4] **Bronnelys:**

- Onderhoud Formaat: Interview Protocol (Creswell, 2014).
- Leidrade vir Vraag 4: Vrae van die CHART assesseringsinstrument wat sosiale deelname van mense met gestremdhede meet (Corrigan & Bogner, 2004) as ook uitdagings ervaar volgens ’n studie deur Gretschel, Visagie en Inglis (2017).
- Leidrade vir Vraag 3: WHO definisie van fasiliteerders (Organisation, 2001).

APPENDIX I: INFORMATION SHEET FOR STROKE PARTICIPANTS



INFORMATION SHEET FOR STROKE PARTICIPANT

Study title: ***Experiences and perceptions of stroke survivors and occupational therapist on community reintegration post stroke in the Western Cape.***

Good day

My name is Hendrina Cecilia Lindner, and I am currently completing my masters in occupational therapy. I am conducting research on stroke survivor's experiences in returning to their communities as well as how occupational therapist in the same area experience rendering services that would help with this process This research is focussed specifically on the Eastern Metro District of the Western Cape.

I would like to invite you to be part of this research by agreeing to participate in an interview. This is voluntary participation, and you may talk to anyone regarding this research. This consent form may contain words that you do not understand, please feel free to ask me. Should you have any questions at a later stage, you are also welcome to ask me.

What is involved in this study?

With this research, I aim to conduct individual interviews with two different sets of participants. One group will be persons who have suffered from a stroke and that received rehabilitation at Western Cape Rehabilitation Centre (WCRC), between one and three years ago, who live in the Eastern Metro District of the Western Cape. The other set will be with occupational therapists that work at the community health care centres in the Eastern Metro District of the Western Cape.

This interview will focus on exploring how you as a stroke survivor have experienced what the facilitators are (that which helps) or barriers (that which is a challenge) that

you have experienced in being able to re-integrate into your community. In other words, how have you been able to participate in activities outside your home that you were involved in before your stroke. All interview questions will be about this. If you decide to participate in this study, you will participate in an hour-long interview conducted by myself.

The interview can take place at your home or the nearest clinic, depending on where both of us are comfortable in meeting. Should you prefer to do the interview telephonically, this can also be arranged. Should you wish to not answer any of the questions during the interview, you may inform myself and we will move on the next question. No one else but I will be present unless you would like so or an interpreter is needed.

Firstly, you will be asked to fill in a questionnaire that has general questions. Should you prefer, the researcher can assist you in completing the questionnaire verbally. This will then be followed by questions that will be asked by myself. There is no right, or wrong answer and the important thing will be for you to explain what your experiences are. During the interview a phone will be used to record what has been said so that this can be studied afterwards.

I aim to conduct ten interviews with 10 persons who have suffered from a stroke. At the end of the interviews and after all the information that has been collected is analysed, two stroke participants will be asked to review how the interview was analysed to make sure that this has been done correctly.

You have been invited to take part in this research because you are someone who has had a stroke and was admitted to WCRC between one and three years ago and live in the Eastern Metro District of the Western Cape.

Risks: There is a risk that some of the information you share is personal or confidential or that by chance you may feel uncomfortable talking about some of the topics. However, you do not have to answer any of the questions that you do not wish to answer.

Benefits: There will be no direct benefit to you through your participation in this research. You will be provided with information on this research while you are involved in the project and when the results are available.

Participation is voluntary: Your participation in this research is entirely voluntary and you can choose whether you would like to participate or not. If you participate in this research, it will have no influence on your work or personal life. After the interview has taken place, you can still request not to participate further in the research. This will mean that your information will not be used in the research study, and it will only be mentioned that one of the participants chose to withdraw from the study.

Reimbursements: You will not be provided with any incentive to take part in this research, but should you have any "out-of-pocket" expenses due to your participation, you will be reimbursed for it, *e.g.,* taxi fares.

Confidentiality: Efforts will be made to keep your information confidential. Absolute confidentiality cannot be guaranteed due to the small area that the research is taking place. There are also authorised organisations such as the Research Ethics Committee, that can inspect and or copy my research record for quality assurance and data analysis. All the information that is recorded will be stored in a secured file on a computer with a password. Only myself, my transcriber and my supervisor will have access to the interviews. The entire interview will be recorded, and during transcription any names that were recorded will be replaced with pseudonyms in the transcription to protect your identity. This data will be destroyed after 6 years.

Contact details of researcher/s:

For any further information or to report any complaints/ problems you are welcome to contact

- Lebogang Maseko, Supervisor, on telephone no. 0735266884, or by e-mail at Lebogang.Maseko@wits.ac.za

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

INLIGTINGSBLAD VIR BEROERTE DEELNEEMER

Studietitel: Die ervarings en persepsies van beroerte oorlewendes en arbeidsterapeute op gemeenskap herintegrasie na ’n beroerte in die Wes-Kaap.

Goeiedag

My naam is Hendrina Cecilia Lindner, en ek is tans besig om my meesters in arbeidsterapie te voltooi. Ek is besig om navorsing te doen oor hoe beroerte oorlewendes dit ervaar om terug te keer na hulle gemeenskappe, as ook hoe arbeidsterapeut in die selfde area dit ervaar om dienste te lewer wat hierdie proses fasiliteer. Die navorsing ondersoek spesifiek die Oosterse Metro Distrik van die Wes-Kaap.

Ek nooi u graag uit om deel te wees van hierdie navorsing deur om in te stem tot in onderhoud. Hierdie is vrywillige deelname en u mag met enige iemand oor hierdie navorsing praat. Indien daar iets is wat u nie nou of op ’n later stadium verstaan nie, moet u my gerus hieroor vra.

Wat behels hierdie studie?

Met hierdie navorsing, beoog ek om individuele onderhoude te voer met twee verskillende groepe deelnemers. Een groep is mense wat ’n beroertes gehad het en rehabilitasie ontvang het by Western Cape Rehabilitation Centre (WCRC) tussen een en drie jaar gelede en wat in die Oosterse Metro Distrik van die Weskaap woon. Die ander stel is arbeidsterapeute wat in die departement van gesondheid klinieke werk in die Oosterse Metro Distrik van die Wes-Kaap.

Hierdie onderhoud sal ondersoek hoe ervaar u die fasiliteerders (dit wat u help) en hindernisse (dit wat vir u moeilik is) om weer deel te word van u gemeenskap nadat u ’n beroerte gehad het. In ander woorde hoe is u in staat om weer deel te neem

aan aktiwiteite buite u huis waarmee u betrokke was voor u beroerte. Indien u besluit om deel te neem aan hierdie studie, sal u gevra word om deel te neem aan ’n uur lange onderhoud met my.

Die onderhoud kan by u huis of naaste kliniek plaasvind, afhangend van waar ons albei gemaklik is om te ontmoet. Indien u dit verkies, kan die onderhoud telefonies ook plaasvind. ’n Tyd sal bepaal word wat vir u sal akkommodeer. Indien u tydens die onderhoud nie een van die vrae wil beantwoord nie, kan u my daarvan inlig en ons sal voortgaan met die volgende vraag. Niemand anders sal tydens die onderhoud teenwoordig wees nie tensy daar ’n vertaler benodig word.

Eerstens sal u gevra word om ’n kort vraelys in te vul wat algemene agtergrondsvrae bevat. Indien u dit so verkies kan die navorser met die die vorm verbaal invul. Daarna sal ek vir u ’n paar vrae, vrae. Die vrae sal gaan oor hoe u dit ervaar het om weer in u gemeenskap te herintegreer vandat u ontslaan is van WCRC en watse faktore mag ’n rol gespeel het. U sal nie gevra word om inligting te deel waarmee u nee gemaklik is om te deel nie. Daar is geen regte of verkeerde antwoorde nie en die belangrike ding is dat u verduidelik wat u ervaring is. Tydens die onderhoud sal ’n telefoon gebruik word om opnames te maak sodat die onderhoud lateraan getranskribeer en bestudeer kan word.

Ek beoog om onderhoude te voer met 10 persone wat beroertes gehad het. Aan die einde van die onderhoude en nadat die inligting wat versamel is geanaliseer is, sal twee van die persone gevra word om te hersien hoe hul onderhoud geanaliseer is om seker te maak dat dit verteenwoordigend is van wat gesê is.

U is uitgenooi om deel te neem aan hierdie navorsing omdat u ’n beroerte gehad, toegelaat was by WCRC vir rehabilitasie tussen een en drie jaar terug en u woon in die Oosterse Metro Distrik van die Wes-Kaap.

Risiko: Daar is ‘n risiko dat van die inligting wat u deel persoonlik en konfidensieel mag wees of dat u moontlik ongemaklik laat voel. Niete wel, u hoef geen vrae te beantwoord nie indien u nie wil nie.

Voordele: Daar sal geen direkte voordele wees vir u deur u deelname aan hierdie navorsing nie. U sal inligting gegee word oor die studie terwyl u by die projek betrokke is as ook wanneer die resultate beskikbaar word.

Deelname is vrywillig: U deelname in hierdie navorsing is heeltemal vrywillig en u kan besluit of u daaraan wil deelneem of nie. U deelname sal geen invloed hê of u persoonlike of werkslewe nie. Na die onderhoud plaasgevind het maag u nog steeds vrae om nie verder deel te neem aan die navorsing nie. Dit sal beteken dat u inligting nie gebruik sal word vir die navorsing nie en daar sal net genoem word dat een van die deelnemers het besluit om van die studie te onttrek.

Vergoeding: Daar sal geen vergoeding wees om deel te neem aan hierdie navorsing nie, maar indien u enige onkostes moet nagaan as gevolg van u deelname, sal u daarvoor vergoed word, *bv*. indien u vervoer onkostes het.

Konfidensialiteit: Alle pogings sal aangewend word om u inligting vertroulik te hou. Absolute vertroulikheid kan nie gewaarborg word nie vanweë die klein area waarin die navorsing plaas vind. Daar is ook gemagtigde organisasies, soos die Navorsing Etiek Komitee, wat die navorsingsrekords mag ondersoek en kopieer vir kwaliteitsversekering en data analise. Alle inligting wat aangeteken is, sal in ’n beveiligde lêer gestoor word op ’n rekenaar met ’n wagwoord. Slegs myself, my transkribeerder en my studieleier sal toegang hê tot die onderhoude. Die hele onderhoud sal opgeneem word en tydens transkripsie sal alle name wat opgeneem is vervang word met ’n skuilnaam om u identiteit te beskerm. Hierdie inligting sal na 6 jaar vernietig word.

Kontak besonderhede vir die navorser/s:

Vir enige navrae of om enige klagtes/ probleme aan te meld is u welkom om die volgende persone te kontak

- Lebogang Maseko, studieleier, per telefoon no. 0735266884, of per e-pos by Lebogang.Maseko@wits.ac.za

Hierdie studie is deur die Universiteit van Witwatersrand, Johannesburg se Komitee vir Menslike Navorsing Etiek (Medies) goedgekeur. ’n Hooffunksie van hierdie

komitee is die regte en waardigheid van navorsingdeelnemers te beskerm as ook die integriteit van die navorsing te verseker.

Indien u enige sorge het oor die manier wat hierdie navorsing uitgevoer word, kontak asseblief die voorsitter van hierdie komitee, Professors Clement Penny, wat gekontak kan word by telefoonnommer 011 717 2301, of per e-pos op Clement.Penny@wits.ac.za. Die telefoon nommers vir die komitee sekretaresse is 011 717 2700/1234 en die epos adresse is Zanele.Ndlovu@wits.ac.za en Rhulani.Mukansi@wits.ac.za.

APPENDIX J: PARTICIPANT CONSENT FORM



PARTICIPANT CONSENT FORM

Experiences and perceptions of stroke survivors and occupational therapist on community reintegration post stroke in the Western Cape.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details:

- Hendrina Cecilia Lindner, Principal Investigator, on telephone no. 0769724898, or by e-mail at celicelindner@gmail.com.
- Lebogang Maseko, Supervisor, on telephone no. 0117173701, or by e-mail at Lebogang.Maseko@wits.ac.za
- Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
- Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011
  717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant: _____

Date: _____

Place: _____

Signature or mark: _____

Witnessed by: _____

Name of Witness _____

Signature: _____

Date: _____

DEELNEMER TOESTEMMINGSVORM

***Ervarings en persepsies van beroerte oorlewendes en arbeidsterapeute op gemeenskap herintegrasie na 'n beroerte in die Wes-Kaap*.**

1. Ek het 'n deelnemer-inligtingsblad ontvang waar die aard en prosesse wat by hierdie studie betrokke is, verduidelik word;
2. Ek het tyd gekry om dit te lees of vir my te laat lees in die taal wat ek die beste verstaan;
3. Ek het tyd gekry om vrae te vra wat ek wou en het enige antwoorde wat aan my gegee het as redelik en bevredigend bevind;
4. Ek glo dat ek ten volle verstaan waarom die studie gedoen word en wat die beoogde uitkomstes sal wees;
5. Ek verstaan dat daar geen direkte voordeel vir my sal wees as ek instem om deel te neem nie, en ek sal ook geen betaling ontvang nie, deelname kos my niks anders as my tyd nie;
6. Ek verstaan dat, selfs al sou ek aanvanklik toestemming gee om aan die studie deel te neem, ek dit op enige tydstip moontlik mag onttrek en nie van enige redes hoef te verskaf nie; indien dit sou gebeur, sou enige gegewens wat oor my ingesamel is vir die doeleindes van die studie onmiddellik vernietig word, tensy ek toestemming gee dat dit behoue bly;
7. Hier is 'n verskeidenheid kontakbesonderhede aan my gegee. As ek verdere inligting benodig of besorg raak oor enige aspek van hierdie studie, is ek vry om met enige van hierdie kontakte te praat.

Kontakbesonderhede:

- Hendrina Cecilia Lindner, Hoof Navorser, per telefoon no. 0769724898, of per epos by celicelindner@gmail.com.
- Lebogang Maseko, Studieleier, per telefoon no. 0117173701, of per epos by Lebogang.Maseko@wits.ac.za
- Professor CB Penny, Voorsitter van die Komitee vir Menslike Navorsing etiek (Medies) van die Universiteit van Witwatersrand, per telefoon no. 011 717 2301, of per e-pos by Clement.Penny@wits.ac.za.
- Ms. Z Ndlovu of Mr Rhulani Mkansi, Komitee Sekretaresse, telefoon no.: 011 717
  2700 of 1234, of per e-pos byt: Zanele.Ndlovu@wits.ac.za of Rhulani.Mkansi@wits.ac.za

Naam van die deelnemer: _____

Datum: _____

Plek: _____

Handtekening of merk : _____

Getuie deur:

Naam van Getuienis: _____

Handtekening: _____

Datum: _____

APPENDIX K: CONSENT FORM FOR AUDIO RECORDING OF STUDY PARTICIPANTS



CONSENT FORM FOR AUDIO RECORDING OF STUDY PARTICIPATION

Experiences and perceptions of stroke survivors and occupational therapist on community reintegration post stroke in the Western Cape.

I hereby consent to audio recording of the interview.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark: _____

Witnessed by:

Name of Witness _____

Signature: _____

Date: _____

TOESTEMMINGSVORM VIR KLANKOPNAME VAN STUDIE DEELNEMER

***Ervarings en persepsies van beroerte oorlewendes en arbeidsterapeute op gemeenskap herintegrasie na 'n beroerte in die Wes-Kaap*.**

Ek gee hiermee toestemming tot die klankopname van die onderhoud.

Ek verstaan dat:

- Die opname gestoor sal word in 'n veilige plek ('n geslote kas of 'n rekenaar met 'n wagwoord) met beperkte toegang vir die navorser en studieleier.
- Die opname sal getranskribeer word en enige inligting wat my kan identifiseer sal verwyder word,
- Die opname sal uitgevee word binne of (a) twee (2) jaar of binne die publikasie van die navorsing bevindings, of (b) ses (6) jaar, indien daar geen publikasies kom van hierdie navorsing nie
- Enige iemand wat hierdie inligting in die toekoms wil kry sal eers toestemming moet kry van die Komitee vir Menslike Navorsing etiek (Medies) van die Universiteit van Witwatersrand, Johannesburg
- Direkte aanhalings uit my onderhoud, sonder enige inligting wat my kan identifiseer, kan in die navorsingsverslag of in ander navorsing opgawes aangehaal word.

Naam van Deelnemer: _____

Datum: _____

Plek: _____

Handtekening of merk _____

Getuig deur:

aam van Getuienis: _____

Handtekening: _____

Datum: _____

APPENDIX L: INFORMATION SHEET FOR OCCUPATIONAL THERAPY PARTICIPANTS



INFORMATION SHEET FOR OCCUPATIONAL THERAPY PARTICIPANT

Study title: ***Experiences and perceptions of stroke survivors and occupational therapist on community reintegration post stroke in the Western Cape.***

Good day

My name is Hendrina Cecilia Lindner, and I am currently completing my masters in occupational therapy. I am conducting research on stroke survivor's experiences in returning to their communities as well as how occupational therapist in the same area experience rendering services that would help with this process This research is focussed specifically on the Eastern Metro District of the Western Cape.

I would like to invite you to be part of this research by agreeing to participate in an interview. This is voluntary participation, and you may talk to anyone regarding this research. Should there be anything you do not understand now or at a later stage, please feel free to ask me.

What is involved in this study?

With this research, I aim to conduct individual interviews with two different sets of participants. One group will be persons who have suffered from a stroke and that received rehabilitation at Western Cape Rehabilitation Centre one year ago, who live in the Eastern Metro District of the Western Cape. The other set will be occupational therapists that work at the community health care centres in the Eastern Metro District of the Western Cape.

This interview will focus on exploring how you as an occupational therapist experience and perceive the facilitators and barriers to rendering services that facilitate community reintegration to stroke survivors. All interview questions will

pertain to this. If you decide to participate in this study, you will participate in an hour-long interview conducted by myself.

In light of the COVID-19 pandemic and to minimize risk, the interview will take place via Microsoft teams of telephonically. A time will be scheduled that will accommodate you. Should you wish to not answer any of the questions during the interview, you may inform myself and we will move on the next question. No one else but I will be present unless you would like so or an interpreter is needed

Firstly, you will be asked to complete a general demographic questionnaire. This will then be followed by questions that will be asked by myself. There is no right, or wrong answer and the important thing will be for you to explain what your experiences are. During the interview a phone or computer will be used to record what has been said so that this can be studied afterwards.

I aim to conduct interviews with all the occupational therapists that are servicing community health centres in the Eastern Metro District of the Western Cape. At the end of the interviews and after all the information that has been collected is analysed, one therapist will be asked to review how their interview was analysed to make sure that this has been done correctly.

You have been invited to take part in this research because you are an occupational therapist that is servicing one or several CHCs in the Eastern Metro District of the Western Cape.

Risks: There is a risk that some of the information you share is personal or confidential or that by chance you may feel uncomfortable talking about some of the topics. However, you do not have to answer any of the questions that you do not wish to answer.

Benefits: There will be no direct benefit to you through your participation in this research. You will be provided with information on this research while you are involved in the project and when the results are available.

Participation is voluntary: Participation in this research is entirely voluntary. If you participate in this research, it will have no influence on your work or personal life. After the interview has taken place, you can still request not to participate further in

the research. This will mean that your information will not be used in the research study, and it will only be mentioned that one of the participants chose to withdraw from the study.

Reimbursements: You will not be provided with any incentive to take part in this research.

Confidentiality: Efforts will be made to keep your information confidential. Absolute confidentiality cannot be guaranteed due to the small area that the research is taking place. There are also authorised organisations such as the Research Ethics Committee, that can inspect and or copy my research record for quality assurance and data analysis. All the information that is recorded will be stored in a secured file on a computer with a password. Only myself, my transcriber and my supervisor will have access to the interviews. The entire interview will be recorded, and during transcription any names that were recorded will be replaced with pseudonyms in the transcription to protect your identity. This data will be destroyed after 6 years.

Contact details of researcher/s:

For any further information or to report any complaints/ problems you are welcome to contact

- Lebogang Maseko, Supervisor, on telephone no. 0735266884, or by e-mail at Lebogang.Maseko@wits.ac.za

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

WITS UNIVERSITY

INLIGTINGSBLAD VIR ARBEIDSTERAPEUT DEELNEEMER

Studietitel: Die ervarings en persepsies van beroerte oorlewendes en arbeidsterapeute op gemeenskap herintegrasie na ’n beroerte in die Wes-Kaap.

Goeiedag

My naam is Hendrina Cecilia Lindner, en ek is tans besig om my meesters in arbeidsterapie te voltooi. Ek is besig om navorsing te doen oor hoe beroerte oorlewendes dit ervaar om terug te keer na hulle gemeenskappe, as ook hoe arbeidsterapeut in die selfde area dit ervaar om dienste te lewer wat hierdie proses fasiliteer. Die navorsing ondersoek spesifiek die Oosterse Metro Distrik van die Wes-Kaap.

Ek nooi u graag uit om deel te wees van hierdie navorsing deur om in te stem tot in onderhoud. Hierdie is vrywillige deelname en u mag met enige iemand oor hierdie navorsing praat. Indien daar iets is wat u nie nou of op ’n later stadium verstaan nie, moet u my gerus hieroor vra.

Wat behels hierdie studie?

Met hierdie navorsing, beoog ek om individuele onderhoude te voer met twee verskillende groepe deelnemers. Een groep is mense wat ’n beroertes gehad het en rehabilitasie ontvang het by Western Cape Rehabilitation Centre een jaar gelede en wat in die Oosterse Metro Distrik van die Weskaap woon. Die ander stel is arbeidsterapeute wat in die gemeenskap gesondheidsorg sentrums werk in die Oosterse Metro Distrik van die Wes-Kaap.

Hierdie onderhou sal ondersoek hoe u as arbeidterapeut dit ervaar om dienste te lewer wat gemeenskap herintegrasie fasiliteer vir beroerte oorlewendes, deur om spesifiek te kyk na fasiliteerders en hindernisse. Alle onderhoudsvrae sal in

betrekking hiermee wees. Indien u besluit om deel te neem, sal u deelneem aan ’n uur lange onderhoud met my.

As gevolg van die COVID-19 pandemie en om enige risiko’s te verminder, sal die onderhoud oor Microsoft Team of telefonies plaasvind. ’n Tyd sal bepaal word wat vir u sal akkommodeer. Indien u tydens die onderhoud nie een van die vrae wil beantwoord nie, kan u my daarvan inlig en ons sal voortgaan met die volgende vraag. Niemand anders sal tydens die onderhoud teenwoordig wees nie tensy daar ’n vertaler benodig word.

Eerstens sal u gevra word om ’n demografiese vraelys te voltooi. Dit sal gevolg word deur vrae wat deur myself gefasiliteer word. Daar is geen regte of verkeerde antwoorde nie en die belangrike ding is dat u verduidelik wat u ervaring is. Tydens die onderhoud sal ’n telefoon of rekenaar gebruik word om opnames te maak sodat die onderhoud daarna getranskribeer en bestudeer kan word.

Ek beoog om die onderhoude te voer met al arbeidsterapeute wat by gemeenskap gesondheidsorg sentrums in die Oosterse Metro Distrik van die Wes-Kaap dienste lewer. Na afloop van die onderhoude en ontleding van die ingesamelde data, sal een arbeidsterapeut gevra word om te hersien hoe die onderhoud geanaliseer is om seker te maak dat dit verteenwoordigend is van wat gesê is.

U word uitgenooi om deel te neem aan hierdie navorsing omdat u een van die arbeidsterapeut is wat by ‘n enkele of ‘n paar gemeenskap gesondheidsorg sentrum in die Oosterse Metro Distrik van die Wes-Kaap dienste lewer

Risiko: Daar is ’n risiko dat van die inligting wat u deel persoonlik en konfidensieel mag wees of dat u moontlik ongemaklik laat voel. Niete wel, u hoef geen vrae te beantwoord nie indien u nie wil nie.

Voordele: Daar sal vir u geen direkte voordele wees deur u deelname aan hierdie navorsing nie. U sal inligting ontvang oor die studie terwyl u by die projek betrokke is as ook wanneer die resultate beskikbaar is.

Deelname is vrywillig: Deelname aan hierdie navorsing is heeltemal vrywillig. U deelname sal geen invloed hê of u persoonlike of werkslewe nie. Na die onderhoud plaasgevind het maag u nog steeds vrae om van die navorsing te ontrek. Dit sal

beteken dat u inligting nie gebruik sal word vir die navorsing nie en daar sal net genoem word dat een van die deelnemers besluit het om van die studie te onttrek.

Vergoeding: Daar sal geen vergoeding wees om deel te neem aan hierdie navorsing nie.

Konfidensialiteit: Alle pogings sal aangewend word om u inligting vertroulik te hou. Absolute vertroulikheid kan nie gewaarborg word nie vanweë die klein area waarin die navorsing plaas vind. Daar is ook gemagtigde organisasies, soos die Komitee vir Menslike Navorsing etiek, wat die navorsingsrekords mag ondersoek en kopieer vir kwaliteitsversekering en data analise. Alle inligting wat aangeteken is, sal in ’n beveiligde lêer gestoor word op ’n rekenaar met ’n wagwoord. Slegs myself, my transkribeerder en my studieleier sal toegang hê tot die onderhoude. Die hele onderhoud sal opgeneem word en tydens transkripsie sal alle name wat opgeneem is vervang word met ’n skuilnaam om u identiteit te beskerm. Hierdie inligting sal na 6 jaar vernietig word.

Kontak besonderhede vir die navorser/s:

Vir enige navrae of om enige klagtes/ probleme aan te meld is u welkom om die volgende persone te kontak

- Lebogang Maseko, studieleier, per telefoon no. 0735266884, of per e-pos by Lebogang.Maseko@wits.ac.za

Hierdie studie is deur die Komitee vir Menslike Navorsing etiek (Medies) van die Universiteit van Witwatersrand, Johannesburg goedgekeur. ’n Hooffunksie van hierdie komitee is die regte en waardigheid van navorsingdeelnemers te beskerm as ook die integriteit van die navorsing te verseker.

Indien u enige sorge het oor die manier wat hierdie navorsing uitgevoer word, kontak asseblief die voorsitter van hierdie komitee, Professors Clement Penny, wat gekontak kan word by telefoonnommer 011 717 2301, of per e-pos op Clement.Penny@wits.ac.za. Die telefoon nommers vir die komitee sekretaresse is 011 717 2700/1234 en die epos adresse is Zanele.Ndlovu@wits.ac.za en Rhulani.Mukansi@wits.ac.za.

APPENDIX M: WITS APPROVAL OF TITLE

UNIVERSITY OF THE
WITWATERSRAND
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

03 January 2020
Person No: 2243766
PAG

Mrs HC Lindner
2 Brand Street
Lochnerhof
Strand
7139
South Africa

Dear Mrs Hendrina Lindner

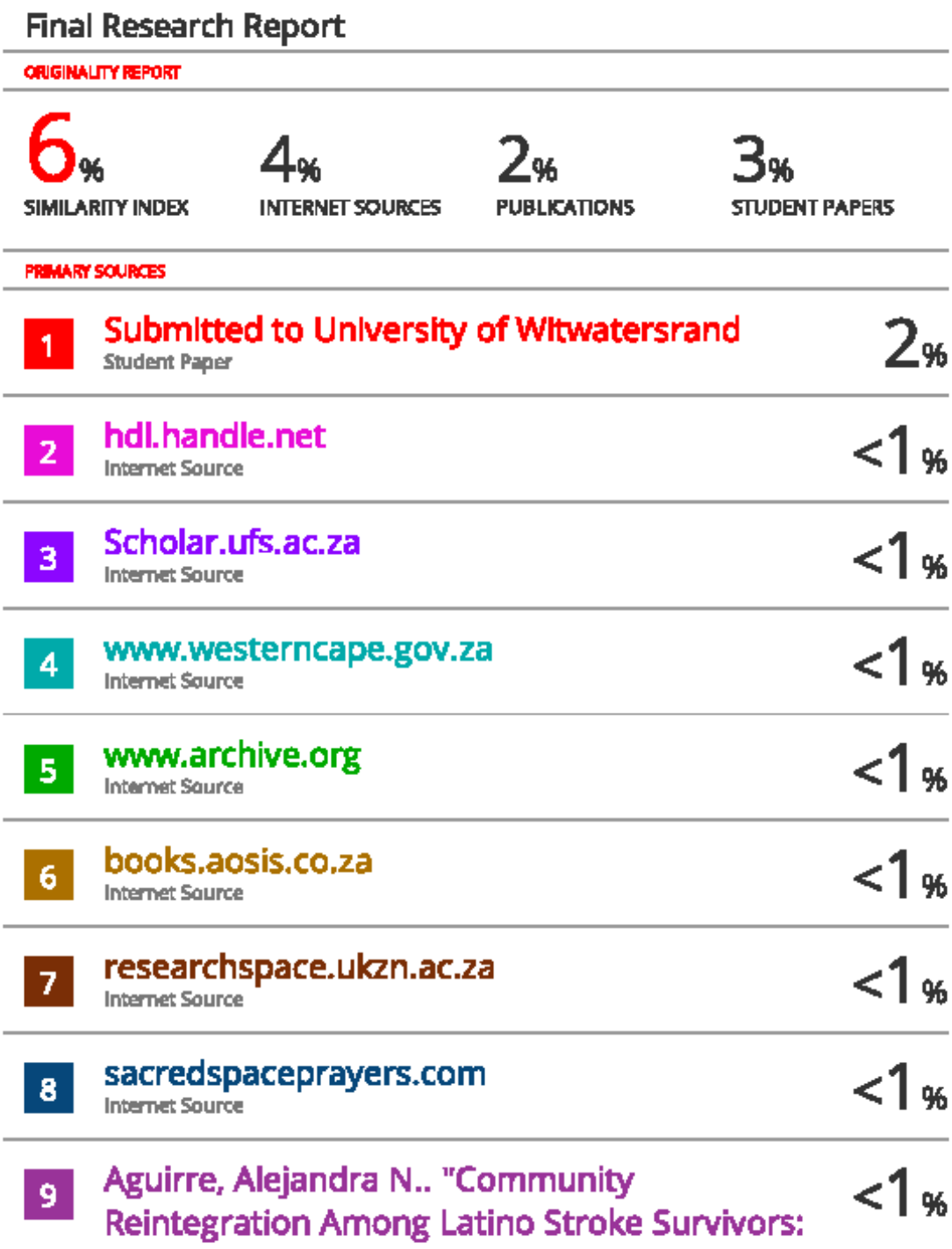
Master of Science in Occupational Therapy: Approval of Title

We have pleasure in advising that your proposal entitled *Experiences and perceptions of stroke survivors and occupational therapist on community reintegration post stroke in the Werstern Cape* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX N: TURN-IT-IN REPORT



Final Research Report

ORIGINALITY REPORT

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