

FACTORS INFLUENCING THE DESIGN OF AN OCCUPATIONAL THERAPY STROKE PROGRAM IN PRIMARY HEALTH CARE

by

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Dissertation submitted in fulfillment of the requirements in respect of the
Master's Degree qualification

MAGISTER IN OCCUPATIONAL THERAPY

Department of Occupational Therapy
Faculty of Health Sciences
University of the Free State
South Africa

(240 Credits)

JUNE 2019

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DECLARATION

I, Catherina Elizabeth Johanna Naudé, hereby declare that the Master's Degree dissertation entitled '**Factors influencing the design of an occupational therapy stroke program in Primary Health Care**', that I herewith submit for the qualification Magister in Occupational Therapy at the University of the Free State, is my independent work. I declare that I have not previously submitted the same work for a qualification at another University. I hereby concede copyright to the University of the Free State.



Catherina Elizabeth Johanna Naudé

29 June 2019

I dedicate this work to my grandmother, Elize de Wet.

Thank you for allowing me to be part of your journey as a patient. I have learnt countless lessons about what life is like to be dependent on others. Thank you for always motivating me to be the best therapist that I can be and for supporting me all the way on my journey through this study.

ACKNOWLEDGEMENTS

I would not have been able to complete this dissertation without the assistance, guidance and support of so many people and institutions. I would hereby like to extend my heartfelt appreciation and acknowledgement to them:

- My parents, Francois and Marina Naudé. Thank you for always believing in me and encouraging me every step of the way. Thank you for all of the opportunities that you have created for me in life. Thank you for the countless dinners and all the prayers that you have sent my way. I am truly thankful and blessed to have you as parents.
- My brother, Eduard Naudé, and grandmother, Elize de Wet. Thank you for your friendship, support and encouragement.
- My dear friend Carin Combrink, you have been a rock for me and I cannot put into words what your unconditional friendship has meant to me during the past few years of this study. Thank you for always providing a listening ear, a shoulder to cry on and being an encourager all of the way.
- To my dear friends, Willie and Jeanette de Jager. Thank you for the numerous times that you opened your house to me in Bloemfontein. I appreciate your friendship and support throughout this journey.
- To my colleague and friend, Rolyn Lathleiff. Thank you for the support in finishing this study and for always having an ear to listen. Your support has come a long way.
- To all my family and friends for your friendship, support and prayers.
- To Me Tlaki Mashego. You have been my number one supporter all along. Thank you for all the motivation and the sacrifices that you made to be able to support me. I am privileged to work with you.
- To my supervisors, Mrs. Elize Janse van Rensburg and Dr. Annamarie van Jaarsveld. Thank you for all your insights, guidance, encouragement and patience with me. Thank you for never giving up on me or this study.

- Thank you to my co-coder and focus group facilitator, Mrs. Juanita Swanepoel. Thank you for sharing your time and insights with this study. Your assistance has made valuable contributions to this study.
- To my interpreter and colleague, Kopano Malebo. Thank you for all the time and effort that you have put into this study. Thank you for sharing my dream of accessible, quality rehabilitation services at our clinics.
- The Free State Department of Health. Thank you for allowing me the opportunity to conduct this study within your Department. Thank you to all my occupational therapy colleagues who have participated in this study. Thank you to each clinic manager who welcomed me with open arms into your clinics. Lastly, thank you to each community health worker who participated in this study.
- Mr. DS Ntsutle, former CEO of Elizabeth Ross District Hospital. Thank you for believing in me and inspiring me to reach higher heights. Thank you for the time that you allowed me to invest in this study, I truly appreciate it.
- Mr. P Radebe, thank you for the support that you have offered me within your institution to complete and present this study. It is highly appreciated.
- Thank you to each stroke survivor who participated in this study and for sharing so many insights from your lives. I salute you for your bravery, perseverance and positive spirits.
- My Heavenly Father for the grace and blessing for the opportunity to have undertaken this study and for the privilege to work with people. All the praise, glory and honor to my Savior!

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LIST OF ACRONYMS

ADL - Activities of daily living
CHWs - Community Health Workers
COPC - Community-Orientated Primary Care
DHS - District Health System
DBST - District Based Specialist Teams
NDoH - National Department of Health
DSR - Design Science Research
FSDoH - Free State Department of Health
HRH - Human Resources for Health South Africa
HSREC - Health Science Research Ethics Committee
MDT - Multi-disciplinary Team
MDTs - Multi-Disciplinary Teams
NDoH - National Department of Health
NHI - National Health Insurance
NPPHCN - National Progressive Primary Health Care Network
NRP - National Rehabilitation Policy
OTASA - Occupational Therapy Association of South Africa
OTPF - Occupational Therapy Practice Framework
PHC - Primary Health Care
SA - South Africa
SASSA - South African Social Security Agency
SASPI - South African Stroke Prevention Institute
TMHD - Thabo-Mofutsanyana Health District
UHC - Universal Health Coverage
UFS - University of the Free State
RuReSA - Rural Rehab South Africa
SA - South Africa
WBOT - Ward Based Outreach Teams
WHO - World Health Organization

CONCEPT CLARIFICATION

For the purpose of this study the following definitions will be applied:

Community Setting

Stedman's Online (2016, p.1) defines the community setting as "A group of people united by some common feature or shared interest; the social context in which professional services are provided. A community may be united by physical or geographic factors, by one or more common characteristics such as age, gender, developmental level, culture, or health or disability status, or by a shared perspective."

Intervention

The American Occupational Therapy Association (2014, p.10) defines intervention as "the plan that will guide actions taken and that is developed in collaboration with the client. It is based on selected theories, frames of reference, and evidence. Outcomes to be targeted are confirmed. Intervention implementation - Ongoing actions taken to influence and support improved client performance and participation. Interventions are directed at identified outcomes."

Non-communicable Diseases

The official web page of the South African Government defines non-communicable diseases as "a medical condition or disease which by definition is not non-infectious and cannot be passed from person to person" (Anon 2019, p. 1). The World Health Organization indicated four types of non-communicable disease that includes cardiovascular diseases (including strokes), cancers, chronic respiratory diseases and diabetes (World Health Organization 2018b, p.1).

Objective measures

For the purpose of this study, the following three terms will be used to measure the objectives of the study. The term **structural measures** indicate the capacity of the health care provider under study in terms of its facilities, resources and systems (Qu et

al. 2010, p.48; see also Agency for Healthcare Research and Quality 2011). For the purpose of this study the current regulatory documents, physical facilities at primary health care level and the human resources available will be explored for structural measures. The term **procedural measures** indicate the rehabilitation interventions, preventative and patient education activities (Qu et al. 2010, pp.48, 49). For the purpose of this study the current Occupational Therapy interventions for stroke patients will be explored within the health care provider under study.

Occupational Therapy

The World Federation of Occupational Therapy (World Federation of Occupational Therapy 2010, p.1) defines occupational therapy as "a client-centered health profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement" (World Federation of Occupational Therapy 2010, p.1).

Primary Health Care

The World Health Organization (1978, p.4) defines primary health care as "essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination". For the purpose of this study the term Primary Health Care will be used to refer to the current model of health care implemented at community levels by the Free State Department of Health, including rehabilitation services..

Rural Area

Hart, Larson and Lishner (2005, p.1149) stated the following: "Defining rurality can be elusive and frequently relies on stereotypes and personal experiences. The term suggests pastoral landscapes, unique demographic structures and settlement patterns, isolation, low population density, extractive economic activities, and distinct sociocultural milieus. But these aspects of rurality fail to completely define "rural" and the definition of rurality used for one purpose may be inappropriate or inadequate for another." For the purpose of this study a rural area will be described as the areas, within the Thabo-Mofutsanyana Health District, with low socio-economic status where access to District Hospitals are limited. Limited access refers to areas where the District Hospital is more than 10 kilometres (Dennill 2015a, p.10) from the patient's home and where the closest health contact point will be a Primary Health Care clinic.

Stroke

Within the study a stroke will indicate a condition where a patient suffered either a ischemic or haemorrhage stroke. Bryer *et al.* (2010, p.755) describes the two types of strokes accordingly: An ischemic stroke is caused by an embolus or thrombosis in the brain while a cerebral hemorrhage is caused by a rupture of a cerebral vessel with bleeding onto the brain.

Stroke Survivor

Woodson (2008, p.1002) defined stroke by stating the following: "Stroke, or cerebrovascular accident (CVA), describes a variety of disorders characterized by the sudden onset of neurological deficits caused by vascular injury to the brain. Vascular damage in the brain disrupts blood flow, limits oxygen supply and to surrounding cells, and leads to brain tissue death or infarction." In order to aid in a clearer indication of the choice of terminology, the term stroke survivor will be used throughout the study to refer to a patient that has been diagnosed with vascular injuries to the brain that caused disrupted blood flow and limited oxygen supply to the brain tissue. The term stroke survivor is further also used frequently in recent literature (Joseph *et al.* (2017); Cawood and Visagie (2016); Cawood, Visagie and (2016); Bergström *et al.* (2015)) Another term, often associated with stroke, is a transient ischaemic attack. Bryer *et al.* (2010,

p.769) defines a transient ischaemic attack as a neurological deficit that lasts less than 24 hours and has spontaneous recovery. It is important to note that this study will not focus on a transient ischaemic attack, but rather on stroke alone as defined above.

Stroke Rehabilitation

Bryer *et al.* (2010, p.775) defined stroke rehabilitation as "a goal-oriented process which attempts to obtain maximum function in patients who have had strokes and who suffers from a combination of physical, cognitive and language abilities". For the purpose of this study the term stroke rehabilitation will be used to refer to the Occupational Therapy treatment that a patient receive to rehabilitate function and occupation in order for the patient to participate optimally in activities of daily living.

Thabo-Mofutsanyana Health District

The Thabo-Mofutsanyana Health District is divided into six Health Sub-Districts that includes the following towns: Mantsopa (Ladybrand, Zastron, Hobhouse, Thaba Patchoa), Setsoto (Ficksburg, Senekal, Marquard, Clocolan), Dihlabeng (Bethlehem, Clarens, Fouriesburg, Paul Roux, Rosendal), Nketoana (Reitz, Petrus Steyn, Lindley, Arlington), Phumelela (Vrede, Warden, Memel) and Maluti-A-Pofung (Kestell, Harrismith, Phuthaditjhaba, Tshiame).

SUMMARY

Key terms: Occupational Therapy, Stroke, Rehabilitation, Primary Health Care, Design Science Research,

Introduction and background: The ideal of making health care services accessible to all people within South Africa, is envisioned through the implementation of National Health Insurance (NHI). The rendering of Primary Health Care (PHC) services is set to form the heartbeat of NHI and therefore a renewed focus is placed on the re-engineering of PHC services. Occupational therapy plays a vital role in the rendering of rehabilitation services within PHC, especially to stroke survivors. Stroke is one of the leading causes of disability globally and it is furthermore one of the top 10 non-communicable diseases in Thabo-Mofutsanyana Health District (TMHD) in the Free State province. Due to the limited availability of district hospitals in the TMHD, most stroke survivors are dependent on receiving occupational therapy services at the PHC clinics. Due to poor staffing norms, occupational therapy services are, however, often out of reach to the majority of stroke survivors within the TMHD. The need to design and develop renewed service delivery models for occupational therapy was identified to ensure that services are accessible to the stroke survivor.

Aim: The aim of this study was to identify the factors that will influence the relevance and feasibility in the design of an occupational therapy program for stroke survivors within a rural PHC setting in the TMHD.

Design and methods: A design science research (DSR) methodology was used for this study. Only phase one of DSR was implemented and both qualitative and quantitative research methods were employed. A total of five activities were executed, namely a document review of public health care documentation, structural observations at PHC clinics within the TMHD, structured interviews with community health care workers (CHWs), semi-structured interviews with stroke survivors as well as a focus group with permanently employed occupational therapists within the TMHD.

Findings: Four groups of factors were identified that will influence the relevance and feasibility in the design of an occupational therapy stroke program for the PHC setting. Structural factors were identified that included the exclusion of occupational therapy in relevant public health care documentation as well as the inaccessibility of PHC clinics. The second group of factors that were identified are procedural factors and include the lack of outcome measures and standards of practice for occupational therapy services to stroke survivors within PHC, the possible inclusion of CHWs in the presentation of an occupational therapy stroke program as well as the possible design of a group therapy program. The third group of factors identified related to the challenges that stroke survivors experience while seeking occupational therapy services within PHC and include the physical and emotional distress post stroke, a lack of knowledge on the benefits of occupational therapy post stroke as well as transportation challenges. The last group of factors that have been identified is the content factors that might be considered for the future design of an occupational therapy stroke program for the PHC setting.

Conclusions: Renewed ways of thinking are needed to overcome the challenges faced within PHC in order to ensure that occupational therapy services are relevant and accessible to stroke survivors. Derived from the factors that have been identified, a framework was designed to assist with the future design of an occupational therapy stroke program for the PHC setting.

Word count:539

CHAPTER 1: INTRODUCTION

1.1. INTRODUCTION

The concept of Primary Health Care (PHC) was introduced globally and endorsed during the *Declaration of Alma-Ata* in 1978 (World Health Organization 1978, p.4). South-Africa (SA) adopted the PHC approach and aligned its health care services with this declaration (Dennill 2015a, p.57). PHC services were introduced in SA as a single means to transform and unify the South African health system, making healthcare accessible to each and every one (Department of Health 2000b, p.7). Since 2010 a renewed focus has been placed on the re-engineering of PHC services in SA (Dennill 2015a, p.66).

The global ideal of making healthcare accessible to everyone is still kept alive. During the fortieth anniversary of the *Declaration of Alma-Ata*, a global conference on PHC was held. During the conference, the *Declaration of Astana* was introduced, reaffirming the commitments made by the *Declaration of Alma-Ata* in 1978 (World Health Organization 2018a, pp.3, 5)

The *Declaration of Astana* stated the following:

*We are convinced that strengthening primary health care (PHC) is the most inclusive, effective and efficient approach to enhance people's physical and mental health, as well as social well-being, and that **PHC is a cornerstone of a sustainable health system** for universal health coverage (UHC). We acknowledge that in spite of remarkable progress over the last 40 years, people in all parts of the world still have unaddressed health needs. Promotive, preventive, curative, **rehabilitative services** and palliative care **must be accessible to all**.* (World Health Organization 2018a, p.5, emphasis added)

*We will prioritize disease prevention and health promotion and will aim to meet all people's health needs across the life course through comprehensive preventive, promotive, curative, **rehabilitative services** and palliative care. PHC will provide a comprehensive range of services and care, including but not limited to*

*vaccination; screenings; prevention, **control and management of non-communicable and communicable diseases**. PHC will also be accessible, equitable, safe, of high quality, comprehensive, efficient, acceptable, available and affordable, and will deliver continuous, integrated services that are people-centered and gender-sensitive. We will strive to avoid fragmentation and ensure a functional referral system between primary and other levels of care. (World Health Organization 2018a, p.6; emphasis added)*

The importance of the global commitment towards PHC services and making healthcare accessible to all has been highlighted by the *Declaration of Astana*. According to the World Health Organization (WHO), knowledge and capacity-building, human resources for health, technology, financing, aligning stakeholder support and national policies as well as the empowerment of individuals and communities, will drive the success of PHC services globally (World Health Organization 2018a, pp.8–10).

Although SA has not yet endorsed the *Declaration of Astana*, it provides a number of opportunities to recommit to the use of PHC as the foundation for the delivery of healthcare services in SA (Mash 2018, pp.1, 2). Mash (2018, p.2) indicated that SA is in the process of introducing national health insurance (NHI) through availing PHC services to all. With the introduction of PHC as the heartbeat of NHI in SA (Department of Health 2017c, p.29), a call is made upon all health service elements to re-engineer its services and align it with global and national policies and guidelines. By implication, the call is also made for the re-engineering of occupational therapy services, specifically within the PHC domain.

This study will focus on occupational therapy service delivery to stroke survivors within the PHC setting. Firstly, this study will focus on occupational therapy services as it is one of the service elements of rehabilitation services that are provided within PHC. Secondly, the stroke survivor population has been chosen as stroke forms part of non-communicable, chronic diseases prioritized within PHC in SA (Department of Health 2000b, p.60). The choice of focus for the study will henceforth be discussed.

Firstly, very little is known regarding the functioning of occupational therapy services specifically within the PHC domain globally as well as in SA (Donnelly *et al.* 2014, p.52; Koverman, Royeen and Stoykov 2017, p.1, 2; Dayal 2010, p.24). Although some evidence on the functioning of occupational therapy within PHC has been published in the Western Cape province of SA (Dayal 2010, p.24), it cannot be generalized to the broader South African population due to differences in context, different population dynamics as well as differences in service delivery models. This study was carried out in the Thabo-Mofutsanyana Health District (TMHD) of the Free State Province of SA. To the knowledge of the researcher, no research has previously been done on the functioning of occupational therapy services within the PHC setting in the TMHD. This study was, therefore, the first in TMHD.

Secondly, this study focused on the stroke survivor population as it is the second largest population group being served by occupational therapists in the TMHD with a number of 629 contact sessions with stroke survivors in 2017 (Free State Department of Health 2017). This study also focused on stroke survivors due to the emphasis that is placed on the management of non-communicable diseases within PHC nationally and globally (Department of Health 2000b, p.60, 73, World Health Organization 2018a, p.6). Again, to the knowledge of the researcher, very little information regarding occupational therapy service delivery to stroke survivors within the PHC setting, is available.

The researcher established that many of the stroke survivors in the TMHD are dependent on PHC services, as many towns in the district only offer access to a PHC clinic. Only a few district hospitals (with employed occupational therapists) are available, implying long travelling distances to these towns to access rehabilitation services. In the TMHD, where the researcher was employed at the time of the research, most District Hospitals utilized an outreach model to provide occupational therapy services to stroke survivors at their closest PHC clinic. Outreach services at PHC clinics assisted in relieving the financial burden on stroke survivors to travel to a District Hospital in another town to attend occupational therapy. However, the researcher has experienced that these services are not readily available at all PHC clinics and that outreach services are rendered from different perspectives by different occupational therapists.

Furthermore, access to a PHC clinic can be just as challenging for the stroke survivor. The researcher has experienced that a lack of suitable assistive devices (e.g. to aid with mobility) and the unavailability of occupational therapy services at some PHC clinics, are burdens to stroke survivors.

The inaccessibility of occupational therapy services in PHC in the TMHD, often leads to stroke survivors not attending these services, ultimately negatively impacting their recovery from stroke. Kautzky and Tollman (2008, p.27) emphasize that stroke survivors living in rural areas are often unable to access rehabilitation services regularly which have a negative impact on their ultimate health status. The burdens that stroke patients within the PHC setting face are substantial and it is evident that the stroke survivor population is facing a number of challenges when seeking occupational therapy services.

Informed by experience, this researcher is aware that occupational therapists in the TMHD, as well as within the broader South African public health care setting, are also facing a number of challenges when rendering services to stroke survivors within the PHC setting. The National Department of Health has indicated that

- the use of a medical model in the provision of rehabilitation services;
- the poor availability of services especially within rural areas;
- the inaccurate referral pathways resulting in poor follow up rates;
- the transport challenges for patients;
- the absence of rehabilitation indicators questioning the effectiveness of the service;
- the human resource challenges, as well as
- limited research on the topic

are all major challenges when rehabilitation services are rendered to people living with disabilities (Department of Health 2015a, pp.8, 9).

The absence of rehabilitation indicators, together with the lack of research and knowledge on occupational therapy service delivery to the stroke survivor population within the PHC setting, are reasons for concern. Not only does it influence the rendering of occupational therapy services within the PHC setting, but also poses challenges for the stroke survivor community.

1.2. RATIONALE FOR THE STUDY

With the renewed global emphasis on PHC and the introduction of NHI (with PHC as its heartbeat) in SA, it is vital that PHC services in SA, the Free State Province and particularly in the TMHD, are re-engineered to ensure a high standard of care as well as accessible services to all. Occupational therapy forms part of the essential services that are rendered within the PHC setting and the profession should, therefore, align its practices accordingly.

However, identified shortcomings hamper the availability and accessibility of occupational therapy services to stroke survivors within the PHC setting, while ensuring its feasibility for the occupational therapists employed in the TMHD. Concerns, therefore, exist regarding the quality, effectiveness and accessibility of occupational therapy rehabilitation services to stroke survivors. The stroke survivor population is further burdened with various disabilities and it is essential that these survivors receive adequate and appropriate health care services to positively contribute to their quality of life.

Available research on occupational therapy rehabilitation services within the PHC setting in the Free State Province, as well as within the TMHD is an additional concern. To the knowledge of the researcher, at the time of this study, no research has been done within these contexts relating to occupational therapy services for stroke survivors. The growing stroke population in the Free State Province of SA, and especially in the TMHD (Free State Department of Health 2016b), together with the current human resource constraints of occupational therapy posts in the TMHD, are reasons for

concern. At the time of the study, only seven permanently employed occupational therapists were employed in the TMHD and from 2016 to 2017, an increase of 4 percent was noted in the total stroke contact sessions in the TMHD (Free State Department of Health 2017). Not only is the management of the growing stroke survivor caseloads difficult for occupational therapists to manage, but the lack of rehabilitation indicators for the PHC setting is further influencing the management of stroke survivors negatively. The challenges that are faced by both the occupational therapist and the stroke survivor are elaborated on in detail in Chapter 2.

With the renewed emphasis placed on the re-engineering of PHC services globally, it is essential for all service elements (including occupational therapy) to evaluate their current models of service delivery in order to ensure appropriate and accessible services. With the growing number of stroke survivors living in rural communities and depending on effective PHC services, it is essential for research to be conducted to ensure that services are rendered in a relevant, feasible and effective manner, whilst ensuring accessibility to the service on a PHC level.

The current model of occupational therapy service delivery to stroke survivors within the PHC setting in the TMHD needs to be investigated, re-evaluated and re-engineered to ensure that relevant and feasible services are rendered. Furthermore, the rendering of occupational therapy services should also be researched from the perspective of the stroke survivor in order to gain a holistic understanding of the opportunities, strengths and weaknesses of the service. Only once this is known, the service can be re-evaluated and re-engineered.

Not only may information gathered from this research provide insight into the current models of occupational therapy service delivery within the PHC setting and the challenges that stroke survivors experience, but it could also be used to develop an appropriate program for occupational therapy stroke rehabilitation. Furthermore, not only may the development of such a program assist in guiding the occupational therapy towards rehabilitation indicators for stroke survivors in PHC, but it could also assist in overcoming a number of challenges faced by both the occupational therapist and the

stroke survivor. The results gathered from this study may eventually contribute to the compilation of comprehensive service packages for stroke survivors in NHI, should the study be conducted on a larger scale with the aim of making the results generalizable to the broader SA context.

This study was thus planned with the future design of an appropriate program for occupational therapy stroke rehabilitation in the TMHD in mind. Design science research (DSR) was chosen as it provided the researcher with the opportunity to, in future, design an occupational therapy program by firstly establishing the relevance and feasibility of such a program and secondly, identifying design principles to design such a program.

The design dimensions that were used for this study included three dimensions, namely structural, procedural and content dimensions. These dimensions are, for the purpose of this research, applied as it is used within the *Clinical Fieldwork Project Guide* from the Department of Occupational Therapy at the University of the Free State (UFS) (Van Jaarsveld and Swanepoel 2019, p.3, 13). These dimensions were developed by clustering identified design principles into structural, procedural and design dimensions with the purpose of assisting the design of a product (Plomp (2009, p.27); Connell *et al.* (1997); Van Jaarsveld and Swanepoel (2019, pp.3, 13)), as well as the artifact evaluation criteria as used in DSR (Nieveen (2009, p.89) and Prat, Comyn-Wattiau and Akoka (2014, pp.5, 6)). These three dimensions cover all the aspects that are necessary to embark on a DSR design process.

Due to the complexity and extensiveness of the information that can be gathered from these three dimensions, this study only focused on the structural and procedural aspects and, therefore, the objectives have been aligned accordingly. The structural aspects referred to the current regulatory documents, physical facilities at PHC level, as well as the human resources available to render occupational therapy services to stroke survivors within the PHC setting (i.e. the context of service delivery). The procedural aspects referred to the rehabilitation interventions, preventative and patient education

activities of the current occupational therapy service that stroke survivors receive within the PHC setting in the TMHD (i.e. the procedures of service delivery).

Although it was decided to exclude the content aspects from the objectives of this study and recommend it for a future study (due to the large amount of data it would produce), some content aspects arose unavoidably during the study. Although it was not an objective of the study when the research was planned, data relevant to content strongly emerged in a number of data sets that needed to be included in an occupational therapy stroke program for the PHC setting. Results relating to content were, therefore, included in the presentation and the results of the study. The reader is cautioned to bear in mind that results relating to content aspects are not comprehensive as content was not specifically targeted during data collection.

DSR was implemented as a research method to allow the researcher to develop design principles that are referred to as 'factors' in this study, with the purpose of ensuring that an occupational therapy program can be designed in future that will be relevant to the population under study but also to the specific healthcare setting under study (PHC in the TMHD). Furthermore, DSR also allowed the researcher to identify the guidelines that need to be considered to ensure that such a program is feasible to execute, given the resources and needs.

1.3. PROBLEM STATEMENT

A growing number of stroke survivors are dependent on receiving healthcare services, including occupational therapy, at PHC level. Occupational therapy services are not always readily available at PHC clinics in the TMHD and stroke survivors may not have access to PHC clinics to attend these services. With the introduction of NHI in SA and the renewed focus on PHC globally, a call is made to revisit the current models of occupational therapy service delivery to stroke survivors within the PHC setting. Research is necessary to design and develop renewed service delivery models for occupational therapy to ensure that services are relevant, thus meeting the needs of stroke survivors, whilst ensuring that these services are feasible within the context of occupational therapy services in the TMHD.

1.4. RESEARCH QUESTION

What are the factors that will influence the relevance and feasibility in the design of an occupational therapy program for stroke survivors within a rural PHC setting in the TMHD?

1.5. AIM OF THE STUDY

The aim of this study was as follows:

To identify the factors that will influence the relevance and feasibility in the design of an occupational therapy program for stroke survivors within a rural PHC setting in the TMHD.

1.6. OBJECTIVES

The aim of this study addresses three key focus areas, namely structural factors, procedural factors and challenge factors. The objectives of the study were as follows:

1. To describe the **structural factors** regarding the regulatory documents within the TMHD on the provisioning of occupational therapy services to stroke survivors within the PHC setting.
2. To describe the **structural factors** regarding the physical environment available to render occupational therapy services to stroke survivors within the PHC setting.
3. To describe the **procedural factors** regarding the understanding of the multi-disciplinary team on the roles of the occupational therapist when rendering services to stroke survivors within the PHC setting.
4. To describe the **procedural factors** that are essential in ensuring occupational therapy interventions for stroke survivors are relevant and feasible.
5. To describe the **challenges** stroke survivors experience while receiving occupational therapy services within a PHC setting. (The challenge factors that stroke survivors experience, were included in the objectives of this study, as addressing these factors are vital to ensure that a future occupational therapy program for stroke survivors will meet the needs of the stroke survivors, as they are at the centre of the program that will be designed in future. The identification of

challenge factors will also contribute to the relevance of such a program for the stroke survivors in the future.)

6. To describe the **content factors** that emerged during the study and that needs to be included in an occupational therapy stroke program. (As mentioned earlier, content was not planned as an objective for the study, but it was included as it unavoidably emerged during the study.)

1.7. RESEARCH DESIGN AND METHODOLOGY

Although a detailed description of the methodology will follow in Chapter 3, this section will provide an overview of the research design and methodology. The researcher approached the study from a pragmatic worldview. This view enabled the researcher to identify factors that will contribute to the designing of a relevant and feasible occupational therapy stroke program due to the emphasis on action and practice, as described by Goldkuhl (2004, pp.21, 22).

Since the researcher was not only interested in interpretive descriptions and also due to the complex nature of this study, involving various stakeholders (cf. 1.6.), neither a pure quantitative nor a pure qualitative study design would have been suitable to answer all of the objectives and meet the aim of this study (cf. 1.5., 1.6.). The researcher, therefore, explored a mixed method study design and was then introduced to Design Science Research (DSR).

It was clear that a DSR approach would be able to meet the aim and objectives of this study, as DSR is aligned with the pragmatic paradigm (Van den Akker *et al.* 2006, p.44, Vaishnavi and Kuechler 2004), offering the researcher the opportunity to answer the research question and meet the objectives for this study. DSR aims to bridge science and practical action (Offermann *et al.* 2009, p.2, Hevner *et al.* 2004, p.78) whilst improving practice and contributing to the body of knowledge (Howie 2016, p.4).

Since both qualitative and quantitative study methods were used, different methods of data analysis were utilized. Details of these methods will be discussed in Chapter 3.

1.8. SIGNIFICANCE OF THE STUDY

This study has significance as it firstly provides scientific results for the functioning of occupational therapy services to stroke survivors in the TMHD. To the knowledge of the researcher, this research is the first of its kind in the Free State province. The results and findings of this study, together with future research, may equip and or support the researcher as well as officials from the Free State Department of Health (FSDoH) to develop outcome measures and to implement monitoring and evaluation strategies for the rendering of occupational therapy services, specifically to stroke survivors, within the PHC setting.

Secondly, this research provides the foundation for continued investigation using DSR methodology, specifically on the topic of occupational therapy services to stroke survivors in the PHC setting. This research will lay the foundation to develop and design an occupational therapy stroke program for the PHC setting in the TMHD that is relevant and feasible. Such a program may have the potential to overcome and address a number of barriers and challenges that are being experienced by both occupational therapists and stroke survivors in the PHC setting, leading to increased accessibility to health care and a better quality of life.

Although the results from this study cannot be generalized to the broader South African population, it may contribute valuable information towards the functioning of occupational therapy services within PHC, especially in light of the planning for and implementation of NHI in SA. The results of this study may assist in developing NHI service packages for stroke survivors in the PHC setting.

Publishing the results of this study in accredited journals and presenting the results at rehabilitation forums or congresses, will be considered with the aim of sharing the insights gathered in this study to improve occupational therapy service delivery to stroke survivors within the PHC setting.

This study was, however, done on a small scale and is not necessarily representative of the larger stroke population in the TMHD. Furthermore, due to time and financial limitations, field visits were only concluded at seven PHC clinics in the TMHD. The

results of this study are only contextually relevant to the TMHD, although it may offer insight for future research in the field of stroke rehabilitation within PHC.

1.9. ETHICAL CONSIDERATIONS

The researcher undertook to maintain a high ethical standard throughout the execution of this research. The ethical considerations will be discussed in detail in Chapter 3 (cf. 3.8.). Ethical guidance was applied as described by Botma et al. (2015, pp.115–126). Before any data were collected, the researcher sought approval from the Health Science Research Ethics Committee (HSREC) of the University of the Free State. After approval was granted by the HSREC (approval number: UFS-HSD2017/0304), the protocol and confirmation of approval of the HSREC (cf. Annexure A) were submitted to the Research Ethics Committee of the FSDoH. Only once approval was also granted from the FSDoH Research Ethics Committee (cf. Annexure B), the researcher commenced with the execution of this study.

Furthermore, the researcher applied ethical principles such as informed consent, voluntary participation, preventing the deception of respondents, preventing the violation of privacy and maintaining a high standard of confidentiality. The researcher further ensured that all actions conducted were ethically sound and that no harm was done to any of the participants in the study. The researcher also took special care in preventing any form of plagiarism in the research proposal and report.

1.10. OUTLINE OF CHAPTERS

The following section will provide an overview of the outline of the chapters that can be expected in this dissertation.

Chapter 1: Introduction and problem statement

Chapter 1 presents an introduction to the problem statement for this study as well as to the research questions, aim and objectives in short. A short review of literature is provided and gaps in the current literature have been identified. This chapter furthermore provides an overview of the research design and methodology and ethical considerations as well as a summary of the outline that can be expected from the dissertation. Lastly, the significance of this study is summarized.

Chapter 2: Literature Review

Chapter 2 provides a comprehensive overview of the relevant literature and key concepts that relate specifically to this study. Literature topics comprise PHC, the re-engineering of PHC, the NHI, occupational therapy services within PHC, the re-engineering of occupational therapy within PHC and finally, stroke survivors within the context of PHC. A number of international studies were consulted as very little information was available, specifically on occupational therapy for stroke survivors within the PHC setting, in SA. However, wherever available, contextually relevant literature was consulted. The following databases were consulted during electronic literature searches: *EBSCOhost*® electronic databases (including *Africa-Wide Information*, *CINAHL*® and *Medline*®). *Google Scholar*® was also utilized to retrieve cited literature sources.

Chapter 3: Research Methodology

Chapter 3 presents detailed information on the research methodology that was followed. This chapter provides an overview of the pragmatic paradigm followed in this study, together with a theoretical overview of the DSR study design that was used. The chapter further elaborates on the operationalization of the DSR study design for this study by making use of both qualitative and quantitative methods. A total of five activities (data generating methods) were included in this study (cf. 1.6.). Each activity is described according to its unit of analysis/study population, selection criteria and sampling, data collection methods, pilot study (where applicable), data collection, data management and data analysis. The chapter further elaborates on the validity and reliability of the data, the quality, rigor and trustworthiness of the data as well as the errors in data collection. A detailed description of the ethical considerations completes this chapter.

Chapter 4: Presentation and discussion of results and findings: Health System and health worker perspective

Chapter 4 provides a detailed description of the results and findings of four activities that relate specifically to the health system and the perspective of the health worker. These activities comprise a document review, structured clinic observations, structured

interviews with community health care workers as well as a focus group with occupational therapists. For each activity a description of the demographic information is given together with a discussion of the data that were obtained from the activity. Since both qualitative and quantitative data gathering methods were used, different methods will be applied in the presentation of the data. For the quantitative data sets, descriptive statistics are used and presented in tables and figures. For the qualitative data sets, Creswell's method of data analysis was used to organize data into themes, categories and codes. Verbatim quotes are used in the qualitative data sets. Triangulation of data was applied throughout the chapter to contribute to trustworthiness.

Chapter 5: Client perspective

Chapter 5 comprises a detailed description of the data gathered from stroke survivors. Chapter 5 focuses intentionally only on the results and discussions gathered from the stroke survivors as the stroke survivor is the most important role player in this study. This chapter provides a description of the participants, where after the data of the semi-structured interviews are presented and interpreted. Creswell's method of data analysis was once again implemented to organize the data into themes, categories and codes. Verbatim quotes are presented and triangulation is also applied.

Chapter 6: Conclusion and recommendation for practice

Chapter 6 depicts the conclusions of this study, the implications for practice as well as future recommendations for practice and research. It also provides a meta-analysis of the results from this study. It further describes the limitations of the study as well as the value of the study. An overall conclusion of the dissertation completes this chapter.

1.11. CONCLUSION

Chapter 1 served to orientate the reader to the study and the dissertation. This chapter aimed at briefly identifying the gaps in the current literature on the functioning of occupational therapy services to stroke survivors within the PHC setting, leading to the rationale, problem statement, question, aim and objectives for this study. The research design and methodology were briefly outlined and the significance of the study was

highlighted. This chapter ended with a summary of what is to be expected from each chapter of this dissertation. Although the problem statement and significance of the study was discussed, the following chapter will provide an in-depth, comprehensive description of the literature that supported the relevance and significance of this study.

CHAPTER 2: LITERATURE REVIEW

2.1. INTRODUCTION

The previous chapter provided an overview of the envisaged contents of the different chapters in the dissertation, with attention focused on the problem statement as well as the objectives of this study. The aim of this chapter, containing the literature review, is to elucidate the problem that has been identified in chapter 1 from the existing literature, and equally important, to provide a foundation for the study within a larger pool of knowledge (Fouche and Delpont 2011, p.134).

This literature search has been an integral part of this research project and the researcher continuously scrutinized literature throughout the study. Various sources of literature were utilized which included academic books, scientific journals accessed through electronic database searches (Medline© with full text, CINAHL© with full text, Africa-Wide Information), presentations at workshops as well as public health care documentation from the National and Provincial Health Departments in SA.

The literature review in this chapter is divided into three main areas that include PHC, occupational therapy and stroke survivors. It is essential to delve deeper into the above-mentioned themes in order to provide insight into the problem statement as well as the research question at hand. When designing a program for the PHC setting, it is of utmost importance to fully understand the compilation, functioning and challenges within this setting. It is furthermore essential to understand the role of occupational therapy within PHC and for this study, the role of the occupational therapist towards the stroke survivor will be explored to aid in identifying factors for the design of an occupational therapy stroke program. As stroke survivors are the heartbeat of this study, exploring their needs and challenges are essential in ensuring that such an occupational therapy stroke program will be relevant and feasible.

2.2. PRIMARY HEALTH CARE

The fundamental approach to service delivery in SA is based on PHC where services are delivered and available as close to the patient as possible (Free State Department of Health 2014) by means of the District Health System (DHS). This study will specifically focus on occupational therapy services to stroke survivors within PHC. It is essential to understand the development and current practices of PHC in SA as well as the challenges that this setting encounters. This information will allow a better understanding of the factors that need to be considered to design a relevant and feasible occupational therapy stroke program for PHC.

This section will investigate the origin of PHC as well globally as in SA while focussing on the current re-engineering of PHC services in SA. The re-engineering of rehabilitation services within the PHC setting will also be surveyed and this section will conclude with an overview of the NHI. A clear understanding of these elements are essential to grasp the extent of the problem statement for this study as the PHC setting differs greatly from other health care settings and thus leaves the health care worker with unique challenges and opportunities. When identifying factors that will influence the design of an occupational therapy stroke program, the context and the milieu of the PHC setting should be fully understood.

2.2.1. Global perspective on Primary Health Care

The development of the concept of PHC already emerged during the 1940s and 1950s (Dennill 2015b, p.2). There was, however, an international concern regarding the accessibility of health care services during the 1970s and this led to the International Conference on Primary Health Care that was held in 1978 (Dennill 2015b, p.3). Following the conference, the philosophy of PHC had an instantaneous effect on the WHO's global strategies and it was also accepted widely by the participating nations (Dennill 2015b, p.4). Consequently, the concept of PHC was introduced and endorsed during the Declaration of Alma-Ata in 1978. The declaration defined PHC as:

"Essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination" (World Health Organization 1978, p.4).

The declaration also states that it includes the provisioning of "... promotive, preventative, curative and rehabilitative services" (World Health Organization 1978, p.4). According to the declaration, these services will differ according to the needs of individual communities, but it will include at least the following:

... promotion of proper nutrition and an adequate supply of safe water; basic sanitation; maternal and child care, including family planning; immunization against the major infectious diseases, prevention and control of locally endemic diseases; education concerning prevailing health problems and the methods of preventing and controlling them; and appropriate treatment for common diseases and injuries (World Health Organization 1978, p.34).

In order to foster positive change, the implementation of PHC should be founded on solid principles that will ensure that health services are available to all. Accessibility, affordability, availability, equity, effectiveness and efficiency are identified as the six core principles of PHC, but these principles cannot be implemented without the political commitment from the governments of the day as their support is crucial (Dennill 2015b, p.10). The implementation of PHC further requires that health services are reorganized in order to ensure that infrastructure enhances the efficient and effective rendering of services. The reorganization of services, therefore, focuses on shifting services to community-based PHC centres, rather than hospital-based care (Dennill 2015b, p.11). To further ensure the effective implementation of PHC, a multidisciplinary approach is non-negotiable and intersectorial collaboration should be sought at all times (Dennill 2015b, p.13). Lastly, the role of the community members themselves should not be overlooked. It is of utmost importance that the community should be active participants

in the management of their own health needs and they should be involved in all processes of delivering services (Dennill 2015b, p.14).

Since the declaration of Alma-Ata, progress has been achieved in the development and implementation of PHC strategies globally. Yet, although there has been an increase in the political commitment towards PHC, disparities between countries persist (Dennill 2015b, p.23). The implementation of PHC is also still challenged by a variety of obstacles, including the inability of governments to ensure that people can access health services equally as well as a lack of supporting environments, leaving the promise of health care for all largely unfulfilled (Kautzky and Tollman 2008, pp.17, 18).

During 1997 a World Health Assembly meeting was held in Geneva by the WHO. During the meeting, there was consensus that despite the challenges faced with the implementation of PHC, the PHC approach was a potentially successful approach that should pave the way for obtaining optimal health for all (Dennill 2015b, p.24). The importance of the prerequisites to ensure successful PHC programs, which included an intersectorial approach, community involvement and appropriate technology, was stressed at this meeting (Dennill 2015b, p.24).

As the WHO continuously seek to address the development of PHC, the global strategy on integrated people-centred health services for 2016-2026 was compiled. Within the strategy, the WHO emphasized the need for universal health care coverage amongst all health users by re-orientating the current model of care to prioritize primary care services within communities globally (World Health Organization 2015, p.4, 5). Kuper (2015, p.34) further emphasized that people living with disabilities should be prioritized to receive universal health care and that universal health care services should also deliver rehabilitation services to people living with disabilities. In order to continue strengthening the PHC systems, PHC strategies should, in addition, seek to address the majority of the health care needs of the patients by focusing on prevention, wellness as well as on empowering patients (Dahl-Popolizio et al. 2016, p.270).

With the international background and imperatives for PHC in mind, the following section will focus on the operationalization of PHC in SA.

2.2.2. Primary Health Care in South Africa

SA developed an initiative called the Community-Orientated Primary Care (COPC) and it was introduced in rural Natal during the early 1940s (Dennill 2015b, p.2). The COPC model was determined by four steps that included defining the population, assessing the health needs of the defined population, implementing effective intervention strategies and evaluating the implementations made (Dennill 2015b, p.3). The COPC strategy was, therefore, one of the forerunners in the development of PHC services as it was the first model of health care service delivery founded on a community-based approach.

The implementation of the COPC strategy, however, met with a number of challenges. With the emergence of separate development (known as *apartheid*) in 1952, the ruling party at that time did not implement the proposals that followed from the COPC model. As health services were segregated, it led to different levels of services being rendered as well as inequalities of services (Dennill 2015a, p.56). In 1960 the COPC model collapsed in SA due to the inability of the COPC supporters to keep the model alive amongst the medical establishments of that time. Ultimately, all progress towards the development of COPC was lost (Kautzky and Tollman 2008, p.20). After the collapse of the COPC model, most of its supporters and practitioners emigrated. This led to the development of COPC in various other countries globally, contributing to the conceptualization of PHC as we know it today (Kautzky and Tollman 2008, p.20).

Health reform in SA only commenced in the 1970s with the introduction of the Health Act (No. 63 of 1977), aiming at providing the entire population with reasonable access to health services (Dennill 2015a, p.57). With the declaration of Alma-Ata in 1978, the National Progressive Primary Health Care Network (NPPHCN) called for the implementation of PHC in SA. Although the National Department of Health attempted to implement PHC during the 1980s and early 1990s, their efforts achieved very little. This was mainly due to the segregation of health care services, failing the egalitarian principle of PHC (Kautzky and Tollman 2008, p.22).

During 1986 the development of a National Health Plan was seen, focusing on the prevention of diseases, utilizing community-centred services to promote health as well as to advocate a multidisciplinary approach and active community participation (Dennill 2015a, p.57). The National Policy for the Health Act (No. 116 of 1990) was introduced thereafter and paved the way for the government to implement PHC services to all people (Dennill 2015a, p.58).

After the abolition of *apartheid*, the South African health care services were reconstructed and transformed in 1994 with the main aim of making health care services accessible to all people (Dennill 2015c, p.197). SA followed the global trend and aligned its health care services with the declaration of Alma-Ata (Dennill 2015a, p.57) striving towards the decentralization of health services and improving accessibility.

This led to the development and presentation of the National Health Plan, introducing a progressive PHC movement (Kautzky and Tollman 2008, p.23). The PHC approach was adopted in order to achieve the outcomes set by the declaration of Alma-Ata such as providing services to the community that addresses their main health problems. The ideal of this approach was to include the community in the planning of these services as well as encouraging all health care workers to work together as a team to address the needs of the community (World Health Organization 1978, p.4,5; World Health Organization 2008a, p.80; Department of Health 2000a, p.1). With the introduction of PHC in 1994, pregnant women and children were exempted from paying health care fees, with the purpose of allowing equity in accessing healthcare services (Statistics South Africa 2015, p.71).

During 2000, the NDoH (National Department of Health) issued a document called *The Primary Health Care Package for South Africa - a set of norms and standards* (Department of Health 2000b, p.1). This document outlined the different services that can be expected on PHC level and included an array of diseases that can be treated at the PHC clinic. The document indicated that the clinic would run services five days a week for at least eight hours a day and access to services would be improved by making the clinic accessible to people within five kilometres from their homes

(Department of Health 2000b, p.11). This document provided a framework for the implementation and operationalization of services within a PHC clinic.

South Africa, unfortunately, faced several challenges in providing services according to PHC as well as aligning its health care services with the declaration of Alma-Ata. The challenges include inaccessible health care services to the people, a lack of human resources as well as poor leadership (Kautzky and Tollman 2008, pp.26, 28). Other challenges include (but are not limited to) the incoherent distribution of financial, physical and human resources as well as ill-prepared health staff to face the challenges of implementing PHC in SA (Naledi, Barron and Schneider 2011, pp.20-21). Although the above-mentioned challenges are burdens to the provision of health care in SA, a number of efforts were made to overcome these challenges. The following section will focus on the above-mentioned challenges that SA has faced and the efforts that have been made to overcome these challenges.

2.2.3. Re-engineering of Primary Health Care Services within South Africa

The previous section provided some insight into the development of PHC as well as the challenges that were faced after 1994. In 2008, 30 years after the declaration of Alma-Ata, the International Health Regulations were introduced in order to advance the renewal of PHC globally (World Health Organization 2008b). The goal of these regulations is to ensure that effective systems will be adopted to regulate and control events that may compromise public health as well as to ensure that a comprehensive PHC approach is implemented (World Health Organization 2008b).

SA aligned its health systems with these regulations in order to transform and strengthen its PHC services with the development of the 10 Point Plan (Naledi, Barron and Schneider 2011, p.18). The 10 Point Plan promoted a renewed focus on PHC as well as PHC re-engineering as the backbone for health care service delivery in SA. According to the South African Health Review of 2017, PHC re-engineering was introduced to overcome the gaps between the planning of PHC services and the implementation thereof (Puoane *et al.* 2017, p.172). These gaps are attributed to the misalignment between policy formation and the implementation thereof that leads to an

imbalance in the access, coverage and quality of health care services (Naledi, Barron and Schneider 2011, p.20; Le Roux and Couper 2015, p.440).

As mentioned previously, the NDoH introduced a 10 Point Plan to support PHC in SA during 2008. This plan included the main goals for the NDoH from 2009-2014 endeavouring to transform the health system and consisted of the following (Dennill 2015a, p.66):

1. *Provision of strategic leadership and creation of a social compact for better health outcomes*
2. *Implementation of National Health Insurance (NHI)*
3. *Improving the quality of health services*
4. *Overhauling the health care system and improve its management*
5. *Improving human resource management, planning and development*
6. *Revitalization of infrastructure*
7. *Accelerated implementation of the HIV and AIDS and Sexually Transmitted Infections National Strategic Plan, and increased focus on TB and other communicable diseases*
8. *Mass mobilization for better health for the population*
9. *Review of the Drug Policy*
10. *Strengthening research and development* (Dennill 2015a, p.66).

During 2010 the discussion document, namely: "Re-engineering PHC in South Africa", was issued by the NDoH, aimed to improve the health profile of users by aligning services with the 10 Point Plan (Dennill 2015a, p.66). This document was seen as a key aspect of policy development as it and sought to provide an integrated and population-based approach to healthcare (Naledi, Barron and Schneider 2011, p.23). The renewed focus on the re-engineering of PHC was also connected to the proposed NHI as well as the Negotiated Service Delivery Agreement (Dennill 2015a, pp.66, 67), attempting to provide a new approach that would incorporate social issues in health care, include community members to endorse basic health care as well as ensuring quality health care services (Dennill 2015a, pp.66, 67; Naledi, Barron and Schneider 2011, p.24).

The importance of this renewed focus on proving healthcare services should not be overlooked, as it is currently prioritised by the NDoH as one of the strategic goals for 2015-2020 (Department of Health 2015b, p.5). The strategic goals of the department entail being population focussed, comprehensive and integrated while ensuring that a good quality of essential health care services is rendered. These goals further aim to strengthen the DHS to be well-functioning and to have health teams that are guided and led at district level (Dennill 2015a, p.67).

In order to strengthen and re-engineer PHC services in SA, the NDoH indicated three streams of PHC re-engineering, namely: ward-based outreach teams, district specialist teams and school health (Department of Health 2011, p.3). For the purpose of this study, only the ward-based outreach teams and the district specialist teams will be discussed, as school health does not have specific relevance to this study.

As mentioned earlier, one of the aims of the re-engineering of PHC is to establish a DHS where health service teams are led at district level. The interventions applicable to re-engineering are the deployment of both ward-based PHC outreach teams as well as district-based clinical specialist teams (Dennill 2015a, p.67). Together these two teams will be responsible for providing communities with preventative, promotive, curative and rehabilitative services (Dennill 2015a, p.69). Services should thus be decentralised to ensure that all members of the community have access to health care services in their immediate environment (ward). The decentralization of services is of utmost importance, as these services are historically only available on a secondary or tertiary health care level. The ideal decentralized system entails that when a patient cannot be managed by the ward-based teams, the district-based clinical specialist teams will provide the patient with specialized services (Dennill 2015a, p.72).

Within each DHS, three types of health care facilities can be found: a PHC clinic, a community health centre as well as a district hospital (Naledi, Barron and Schneider 2011, p.24). Patients will enter the health care system by making contact with the PHC outreach team nearest to their homes. If necessary, they will then be referred to the PHC clinic where a doctor, PHC nurse, nurse, pharmacy assistant and a counsellor

should be available. If the patient cannot be managed by the PHC clinic, he/she will be referred to the district hospital or the district base specialist team. The district management team will be responsible for all of the activities in the district while the office of standard compliance will monitor the quality of the services being rendered. These services will be provided together with a school health service as well as in conjunction with the local government to account for the social determinants of health.

The different components of the proposed re-engineering of PHC services will henceforth be discussed as well as the current level of implementation of these elements.

2.2.3.1. Ward-based outreach teams

Ward-based outreach teams (WBOT) form the basis of the proposed PHC approach in SA. Wards are smaller areas of a district and each ward will be allocated with at least one outreach team. The outreach team will be responsible for 1500 families (determined by the number of households) and they will be providing preventative, promotive, curative and rehabilitative services to families (Dennill 2015a, p.68, 69). In order to ensure that services are decentralized effectively, an extended health team is needed that also includes CHWs who will work together with the outreach teams (Dennill 2015a, pp.67, 68). The outreach team will consist of a professional nurse (also called PHC nurse), six CHWs, a health promoter and an environmental health practitioner (Dennill 2015a, p.68).

There are a number of concerns with the currently proposed model for ward-based outreach teams. Firstly, the team does not have any allied health professionals trained in rehabilitation. However, it is expected of the team to provide rehabilitative services, thus raising questions as to whether the team will be able to fulfil all of the services they are expected to provide. Secondly, Dennill (2015a, p.69) mentions that there is a shortage of PHC nurses and this causes a challenge for the outreach teams. Thirdly, the proposed ward-based outreach teams rely heavily on CHWs who are not necessarily adequately trained and equipped. It is important to explore the above-

mentioned concerns further as it can have a devastating effect on the delivery of a quality health care service.

The re-engineering strategy ensures that PHC services are provided at household level by the CHWs (Statistics South Africa 2015, p.71). The proposed roles of the CHWs will include conducting assessments and identifying health needs, providing simple health interventions to households as well as referring patients for further assessment (Department of Health 2011, p.4). It is, however, still unclear how effective CHWs have been integrated into the system as limited research is available on CHWs in PHC in SA. Furthermore, there are no formal databases or training for CHWs and there is a lack of supervision for these health workers (Dennill 2015a, p.71). It is of great concern that CHWs are not formally trained or supervised, as this may lead to the poor implementation of the ward-based outreach teams as well as to poor accessibility to services at household level. The poor integration of CHWs into the PHC system may further influence the correct referral of patients in need of more specialized services.

In addition to the re-engineering of PHC services and the use of ward-based outreach teams, there is also a need to strengthen the DHS (Department of Health 2011, p.1). According to the NDoH (Department of Health 2011, p.1), PHC services on community level (provided by the WBOT) are rendered together with the assistance from the DHS. The proposed model for the DHS will henceforth be discussed.

2.2.3.2. District-based specialist teams

There is a paucity of information on the District-Based Specialist Teams (DBST) and discrepancies exist between different sources on the functioning of the DBST. In the work of Dennill (2015a, pp.45–89), very little mention is made regarding the DBST. It is only mentioned that these teams will be responsible for assisting with difficult cases that are not within the scope of practice of the PHC nurse. The different members comprising the team are further not identified clearly as it is only vaguely mentioned that doctors, emergency personnel and other specialists will be working in this team (Dennill 2015a, p.72). On their turn, the NDoH (Department of Health 2011, pp.6, 7) indicated that the DBST will focus on reducing the high infant, child and maternal mortality rate

and that the specialist team will include a gynaecologist, a paediatrician, an anaesthetist, a family physician, an advanced midwife and a PHC nurse. No mention is made regarding other professions or other illnesses.

Rural Rehab South Africa (RuReSA 2011, p.7) indicated that there is a complete lack of mentioning rehabilitation services within the three streams of PHC services and, moreover, no rehabilitation specialist is mentioned under the DBST. RuReSA (2011, pp.7, 8) advocates that rehabilitation therapists must be included in the PHC teams as well as within the DBST. One of the strategies indicated in the National Rehabilitation Policy (NRP) (Department of Health 2000a, p.13) stipulates that rehabilitation therapists should be included on the district level as part of the referral team. This has however not realized yet, eighteen years after the introduction of this policy. These concerns are further also supported by Leland *et al.* (2017, p.3) who indicated that rehabilitation officials are often overlooked when describing interdisciplinary team functioning within PHC.

Not only will the lack of a clearly specialised team influence the provision of healthcare services to people, but the DBSTs are further run from regional government authorities leading to a "one size fits all approach" that is not effective (Dennill 2015b, p.27). There are a number of other challenges faced by the DBST and these include poor referral systems; poor monitoring and evaluation strategies; services rendered are mainly curative in nature as well as poorly defined roles and responsibilities (Dennill 2015b, p.27).

According to the researcher, it is therefore noteworthy that the **teams are still in need of further development and expansion**. Further investigation and research are necessary to determine the causes of the above-mentioned challenges in order to ensure that the district-based support teams are composed and operationalized effectively. This includes investigating the inclusion of rehabilitation personnel, such as occupational therapists, physiotherapists and speech therapists, into the DBST to ensure that rehabilitation service is rendered effectively.

2.2.4. Re-engineering of Rehabilitation Services within the Primary Health Care domain

The Primary Health Care Package for South Africa - a set of norms and standards indicated that rehabilitation services are one of the integral service elements within PHC (Department of Health 2000b, p.73). Prior to 2000, the rendering of rehabilitation services was mainly institutionally based and rendered mostly secondary and tertiary levels of care (Williams, Maseko and Buchanan 2017, p.2). *The Primary Health Care Package for South Africa - a set of norms and standards* (Department of Health 2000b, p.73) argues that rehabilitation services within PHC are currently in a process of shifting from institution-based services to a service being rendered within the community, correlating with the decentralization of health services within the re-engineering of PHC. The rendering of rehabilitation services and the essential part it has to play within PHC is further emphasized in the NRP (Department of Health 2000a, p.7). According to the NRP, rehabilitation services within PHC must be accessible, affordable, appropriate and acceptable (Department of Health 2000a, p.7).

Although the rendering of rehabilitation services within the PHC domain is considered, the ideals mentioned above are not achieved. The NDoH acknowledges that rehabilitation services in SA are currently facing a number of challenges including inaccessible services to people living in rural areas as services are mainly institution-based (Department of Health 2000a, pp.1, 3, 14). The Department further acknowledges that a shortage of rehabilitation personnel exists in SA, that services have not met the needs of the population and that little research has been done in this field (Department of Health 2000a, pp.4, 28). These challenges are further supported by the Occupational Therapy Association of South Africa (OTASA) (OTASA 2017, p.54) who stated that patients still have limited access to rehabilitation services in SA and that this is mainly due to human resource constraints, services that are located in facilities and poor access to transport.

The importance and purpose of rehabilitation services as well as ensuring that these services align with global and national trends of re-engineering should not be

overlooked amid all these challenges. The purpose of rehabilitation services within PHC are described as follows:

... prevent disabling conditions, to detect disabilities early so to prevent complications and the worsening of the effects of a disability on a person's functional ability, to treat disabling and potentially disabling conditions and to provide access to rehabilitative services for people with disabilities, making them appropriate and acceptable (Department of Health 2000b, p.67).

As mentioned before, the integration of rehabilitation services into the PHC-model has been neglected after the re-engineering of the PHC was implemented (Health Systems Trust 2017, p.16). In order to address this gap, the NDoH developed a document called the Policy Framework and Strategy for Disability and Rehabilitation Services in South Africa (Health Systems Trust 2017, p.16). This strategy was introduced in 2015 and the implementation of the strategy will work towards making rehabilitation services available and appropriate by improving the monitoring and evaluation of the services as well as improving human resources within the rehabilitation domain (Department of Health 2015a, p.11).

With this strategy, the NDoH has placed a renewed focus on the re-engineering of rehabilitation services, making these services inextricable from the full range of PHC services. The document, however, acknowledges that the implementation of rehabilitation services within PHC are facing a number of challenges and that a comprehensive plan needs to be developed in order to foster positive change (Department of Health 2015a, p.9).

The NDoH stated in their performance report for 2016/17 that one of the strategic objectives was to *improve access to disability and rehabilitation services through the implementation of the framework and model for rehabilitation and disability services* (Department of Health 2017b, p.42). The report indicated that eight of the nine provinces in SA currently have implementation plans, but no information was provided whether these plans are implemented or if any progress has been made. This raises

concern as it indicates that the provision of rehabilitation services (specifically on a PHC level) is not monitored as a matter of urgency by the NDoH.

Due to the lack of proper implementation and monitoring of policies, South African allied health professionals are experiencing a dearth of primary care recommendations to implement within the PHC context (Dizon *et al.* 2016, p.2). Despite the lack of recommendations, the vital role that the allied health teams play cannot be overlooked (Dizon *et al.* 2016, p.2; RuReSA 2011, pp.4–9). Ned, Cloete and Mji (2017, p.5) appealed that rehabilitation services should be seen as a necessity within PHC as these services can assist people with disabilities to integrate into their communities and to ensure their active engagement. Rehabilitation services assist in achieving these goals as it advances the wellness and quality of the life of patients, enabling them to engage, participate and integrate into their communities (Ned, Cloete and Mji 2017, p.5).

The re-engineering of rehabilitation services within PHC is, therefore, a necessity to ensure that patients are given the opportunity to advance their health, wellness and quality of life. Rehabilitation officials should, therefore, advocate the inclusion and re-engineering of their services within the PHC team as well as within the DBST.

The following section will focus on NHI as it has a definite influence on the functioning of PHC as well as the provision of rehabilitation services within the PHC domain.

2.2.5. National Health Insurance

A task team was appointed in November 2009 to develop the NHI Policy under the former Minister of Health, Dr Aaron Motsoaledi (Dennill 2015c, p.224). NHI was proposed to ensure that access to healthcare is improved since only 16% of the population is currently making use of private healthcare and 80% of the population is served by the public healthcare sector (Dennill 2015c, pp.224, 225); leading to an unequal rendering of healthcare services.

NHI is defined as a “...*health care financing system that is designed to pool funds to actively purchase and provide access to quality, affordable personal healthcare services for all South Africans based on their health needs, irrespective of their socioeconomic*

status” (Department of Health 2017c, p.3). The NHI will aim at providing progressive universalism and comprehensive services by means of a mandatory prepayment of healthcare while further ensuring financial risk protection and a single fund that will be used to provide for the healthcare needs of the population (Department of Health 2017c, p.8). NHI will further be publicly administered and it will pay for all of the healthcare costs of the population as the NDoH will be purchasing the services that are needed (Department of Health 2017c, pp.8, 9). The department hopes to achieve these aims by implementing a number of principles that include the right to access health care, social solidarity, equity, affordability, efficiency, effectiveness, appropriateness and healthcare as a public good (Department of Health 2017c, p.9).

As demonstrated above, the purpose of the policy document on NHI is to ensure universal, equal health coverage to all South Africans (Department of Health 2017c, p.1). The NDoH aims to achieve this by strengthening PHC as well as to re-engineer the current PHC services by improving leadership and governance within the health system (Department of Health 2017c, p.2). The department further prioritized providing services to vulnerable population groups including people with disabilities by making services portable and providing services close to where these people live (Department of Health 2017c, p.2).

PHC stands central to the implementation of NHI (Department of Health 2017c, p.29) and one of the main motivations behind providing PHC services within NHI, is due to a high number of people who are unable to access health care services due to their topography and unaffordable transportation expenses (Department of Health 2017c, p.24). The policy document supports the structure of PHC, as mentioned earlier, that includes the WBOT, school health and the DBST. The policy document, however, also includes the contracting of private health practitioners to increase access to healthcare within PHC (Department of Health 2017c, p.29).

The policy document further indicated that PHC services should comprise of health promotion, preventative, curative, rehabilitation and palliative services (Department of Health 2017c, p.29). It is noted again that rehabilitative services are essential, but

additional information and a description of rehabilitation services are scant. The policy only stated that disability healthcare services would be provided and fully integrated into PHC, but no specific indication was given regarding the integration of rehabilitation personnel into the system and no mention was made regarding the WBOT or the DBST (Department of Health 2017c, pp.24, 30). The policy further stated that rehabilitation services would be provided as a comprehensive service with regards to assistive devices, prosthesis as well as providing assistive mobility devices (Department of Health 2017c, p.24). The lack of clearly stipulated guidelines for rehabilitation personnel was also noted by RuReSA (2011, p.4) who stated that rehabilitation personnel were scarcely mentioned in the NHI documentation and that attention should be given to this as a matter of urgency.

Although the NHI policy aims at providing accessible healthcare as well as rehabilitation services to the population of SA, the policy in its current form does not provide adequate and specific information with regard to the rehabilitation healthcare provider. This necessitates further research to determine how rehabilitation services can be successfully implemented within PHC through the NHI initiative.

2.2.6. Conclusion: Primary Health Care

Despite all the above-mentioned efforts that have been made to strengthen the re-engineering of PHC in South Africa, very little progress has been made on grass root level. Le Roux and Couper (2015, p.440) argue that the current re-engineering of PHC services is unsuccessful and that the goals thereof have not been reached yet. This is also supported by Statistics South Africa (2015, p.73) who stated that progress within the PHC area is slow.

There are a number of reasons for the challenges and slow progress that are being experienced within PHC implementation and development. The results from a case study done at a PHC facility indicated that a gap persists between policy and the implementation thereof (Draper, Draper and Bresick 2014, p.5). Dookie and Singh (2012, p.2) pointed out challenges with the implementation of PHC and these include resource constraints, lack of human resources as well as the non-optimal use of

resources. This is further supported by Statistics South Africa (2015, p.74) that highlighted uneven implementation of programs as well as several additional weaknesses within the healthcare system.

In addition, the current provision of health services is mainly focused on selective primary care while the initial goal of PHC was to deliver an integrated service (Dookie and Singh 2012). PHC is currently also inadequately implemented and healthcare professionals are equipped poorly (Ned, Cloete and Mji 2017, p.2). Human Resources for Health South Africa (HRH) further indicated that health science graduates are not absorbed in the public health care sector after completion of their community service year (Human Resources for Health South Africa 2011, p.33), leading to inadequate numbers of healthcare personnel. The HRH stated that allied health care, and in particular absorption of occupational therapy and physiotherapy, is low due to the lack of public sector posts. However, there is a great need for these allied health professions, particularly within the public sector.

According to this researcher, the re-engineering of PHC services is therefore still underdeveloped and needs a multi-disciplinary focus with the collaboration of all stakeholders within the health care system to achieve better health outcomes for all. Once these goals have been achieved, PHC services in SA will align with the WHO's strategy for integrated people-centred services and only then will it achieve successful NHI implementation in SA. As this study is situated within the PHC context, it is of vital importance to investigate the current practices for rehabilitation personnel, in particular for the occupational therapist, within PHC to ensure that newly developed programs will meet the needs and be able to overcome challenges that are experienced in the PHC context. When designing an occupational therapy stroke program for the PHC context, the aims of PHC and NHI should be kept in mind. As this investigation is focussing on the development of an occupational therapy program, the following section will look closely at the profession and its role within PHC.

2.3. OCCUPATIONAL THERAPY

The profession of interest in this study is occupational therapy. This section of the literature review will deal with the profession and the services that the occupational therapist can offer within the PHC context. With reference to the previous section on PHC re-engineering; the re-engineering of occupational therapy services within PHC in SA as well as the challenges that are faced by occupational therapists within PHC will be scrutinized.

Having a clear understanding of the above-mentioned aspects will ensure that the reader is provided with insight into the need for the design of an occupational therapy program for the PHC domain. A successful program can, however, only be developed once the challenges and the opportunities faced by the occupational therapist is fully understood. This, together with an understanding of the context and setting under study, will allow the researcher to design a relevant and feasible program for stroke patients. Occupational therapy and how the PHC domain can benefit from the profession will henceforth be explored.

2.3.1. Occupational therapy services within Primary Health Care

Occupational therapy is defined in the Occupational Therapy Practice Framework (OTPF) as “... *the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community and other settings*” (American Occupational Therapy Association 2014, p.1). According to the OTPF, occupational therapy services are rendered to clients with both disability and non-disability related needs with the goal of providing habilitation, rehabilitation, wellness as well as the promotion of health to clients (American Occupational Therapy Association 2014, p.1).

When considering the aforementioned information on PHC (cf. 2.2.2, 2.2.3), the healthcare needs of patients in SA and the definition of occupational therapy, it is evident that the occupational therapist plays a vital role in the management of patients,

especially those with disabilities impacting on daily life occupations, such as the disabilities experienced following a stroke. The researcher acknowledges that in order to foster positive changes and to ensure that rehabilitation services are integrated into PHC successfully all members of the rehabilitation team must be consulted. The researcher further acknowledges that proper multi-disciplinary collaboration is necessary and that each member in the rehabilitation team has a unique and important role to play. However, for the purpose of this study, the focus will be placed on occupational therapy services within the PHC rehabilitation context including the influence that other team members have on the provision of occupational therapy services.

McColl et al. (2009, pp.1524–1527) described six models that can be implemented to integrate rehabilitation and occupational therapy services into PHC: the clinic model; outreach service model; self-management model; community-based rehabilitation model; case management model as well as the shared care model. Of these six, the most common models were found to be the clinic and outreach models (McColl et al. 2009, p.1528). Making use of the outreach model correlates with the WBOT and the PHC clinic model that is currently being implemented in SA. Despite having a model available, limited information is available on what an occupational therapy outreach service in PHC should comprise of. Different literature sources indicate a number of services that can be rendered within PHC. Muir (2012, p.507, 508) stated that the possibilities of occupational therapy within PHC are endless and added that the occupational therapist working in PHC can assist by providing the following services:

- *Early intervention to prevent disease or disability*
- *Identifying how symptoms are affecting function and participation*
- *Provide simple interventions that can be done at home*
- *Enable or improve participation in occupations through activity modification or adaptive equipment*
- *Provide group education or intervention sessions (Muir 2012, p.507, 508).*

Leland *et al.* (2017, p.3) further added that occupational therapists can address a patient's functional needs from an occupational performance perspective by fostering engagement while providing training and education on self-management skills to ensure optimal participation. The therapeutic intervention of occupational therapists is therefore comprehensive as it addresses the patient's habits, roles and routines (Leland *et al.* 2017, p.4) as described in and correlating with the OTPF.

Although the occupational therapist is acquainted with all the aforementioned information, service within the PHC domain stays inadequate. Donnelly *et al.* (2014, p.52) and Koverman, Royeen and Stoykov (2017, p.1, 2) highlighted the fact that despite the support that has been given to promote occupational therapy within PHC, there still is inadequate information available regarding the profession's functioning as well as outcomes for patients. Adding to this, very little research has been done on OT in PHC in SA. Evidence on the functioning of occupational therapy within PHC has been published in the Western Cape province (Dayal 2010, p.24), but this cannot be generalized to the broader South African population due to differences in context, different population dynamics as well as differences in service delivery models. This poses a great challenge for all occupational therapists working within PHC in different South African contexts, calling for further research on the topic.

Due to the little research results available, the occupational therapist working within the PHC domain may find it difficult to integrate and establish an occupational therapy service, therefore, strengthening the call for further research. This study, therefore, is of vital importance as no research has been done previously on the functioning of occupational therapy within PHC, especially in the Free State province of SA. **The aim of this study is to explore and identify the factors that will influence the relevance and feasibility of an occupational therapy program that can be implemented in the Free State province.** These factors will be identified by exploring the context, geographical areas, policies, multi-disciplinary team collaboration as well as the needs of occupational therapy patients within the FSDoH. The conclusion that will be drawn from exploring all of the aforementioned aspects will add to the current knowledge base of research for occupational therapy practices within the PHC context in SA.

The possibilities for occupational therapy intervention within PHC are indeed endless. In the opinion of the researcher, further research and investigation are crucial to ensure that therapists are equipped to provide a comprehensive occupational therapy service within PHC. In order to achieve such a service, the following section will focus on how the current occupational therapy service delivery can be re-engineered within the PHC domain.

2.3.2. Re-engineering of occupational therapy services within Primary Health Care

With the renewed focus of the NDoH on the re-engineering of PHC in SA, it is critical for occupational therapy services to also be re-engineered in order to be suitable for the South African context. Emphasis should be placed on evidence-based practice as well as effective, appropriate and accessible occupational therapy services in order to foster positive change within the PHC context (OTASA 2015, p.58). OTASA has expressed its support towards the NDoH for the implementation of the principles of PHC in SA as well as towards the development of evidence-based practice for occupational therapy services that are rendered within the PHC domain (OTASA 2015, p.58). Occupational therapy and its role within PHC is not new, however, it is of essence that the expectations of the occupational therapist must be clearly stated within the new context of PHC re-engineering (Naidoo, Van Wyk and Joubert 2016, p.7) to ensure the successful delivery of services.

According to recent research, occupational therapists focus mainly on educational sessions within the PHC domain and other occupational therapy related therapeutic services are mainly focused on within the hospital setting - thus implicating that occupational therapy practice is not aligned with PHC principles (Naidoo, Van Wyk and Joubert 2016, p.7, 8). According to the researcher, when considering PHC principles, the health care services should be brought to the patient, implying that all service elements should be made available, not only health promotion. The researcher has experienced that rendering therapeutic services within PHC has greater value to patients than only providing health promotion, as patients are seeking assistance to

engage with various activities as well as to reintegrate into their communities. The researcher further experienced that the patients often only have access to PHC services and do not always have the means to receive these additional therapeutic services at a hospital.

As mentioned previously, the opportunities for the occupational therapist within PHC are endless. It is evident that the occupational therapist can provide more than just health promotion as they are skilled in a number of competencies. These competencies can assist in addressing a number of gaps that are currently experienced within the PHC domain. The occupational therapist can further contribute greatly to the interdisciplinary team with regards to the management of patients. Unfortunately, the role of the occupational therapist in PHC is often overlooked and misunderstood leading to the exclusion of the occupational therapist as part of the team (Dahl-Popolizio *et al.* 2016, pp.270, 271). Metzler, Hartmann and Lowenthal (2012, p.268) and Dahl-popolizio *et al.* (2017, p.9) indicated that occupational therapists need to advocate their competencies as well as the roles that they can fulfil within PHC. As mentioned under 2.2.1, rehabilitation services are not formally designated as part of the services to be provided within the PHC domain. The rehabilitation services also include the occupational therapist and Metzler, Hartmann and Lowenthal (2012, p.268) indicated that one of the challenges that are faced by occupational therapists, is that of not being listed as a PHC service provider.

Metzler, Hartmann and Lowenthal (2012, p.268), however, are adamant that an alignment does exist between occupational therapy services and PHC needs. The occupational therapist should, therefore, form part of the inter-professional team that render services on PHC level (Dahl-popolizio *et al.* 2017, p.8) and this should motivate the occupational therapist to advance the inclusion of the profession within the PHC team. Dahl-popolizio *et al.* (2017, p.8) indicated that primary care providers would be willing to include the occupational therapist to their team if they are given the necessary information on the potential contributions that the occupational therapist can deliver to patient care.

Although OTASA has given its support towards the implementation of PHC in SA, very little research is available on the re-engineering of occupational therapy services with specific reference to PHC in SA. The lack of literature does not only call for further research, but it also calls for a renewed focus on the re-engineering of occupational therapy services within PHC as well as for the profession to promote its competencies. It is however of vital importance to fully understand the functioning of the service within PHC as well as the challenges that are encountered in order to re-engineer. Therefore, the following section will focus on the challenges that occupational therapists encounter when delivering services within PHC.

2.3.3. Challenges faced by Occupational Therapists working within Primary Health Care in the Free State

Due to the limited information on the functioning of occupational therapy within PHC, it can be expected that therapists will face a number of challenges. McColl (1998:11,16) already pointed out in 1998 that occupational therapy rehabilitation in the community can be challenging and that there is a great need for extensive theory development. Although twenty years have passed since McColl's publication, therapists are still struggling to fully provide in the rehabilitation needs of the community as demonstrated by a study done on managers and operations staff working within a South African health district (Dayal 2010, p.25). Dayal (2010, p.25) found that participants centralized their discussions on the obstacles they encounter as they attempt to carry out their professional duties while providing rehabilitation services within the DHS. Managers especially find it difficult to align operational policies to national policies as limited guidance is provided on service delivery and managers are expected to rely on their own experiences rather than on policies where gaps in service delivery are not addressed (Dayal 2010, pp.24, 25).

In more recent studies, Dahl-Popolizio *et al.* (2016, p.271) and Donnelly *et al.* (2014, p.56) also indicated that the occupational therapist encounters challenges in the PHC domain. Some of these challenges include high caseloads [(Donnelly *et al.* 2014, p.56);(McColl *et al.* 2009, p.1529)] and limited time to spend with patients (Dahl-

Popolizio *et al.* 2016, p.271). McColl *et al.* (2009, p.1529) adds that rehabilitation personnel are ill-prepared for rendering services as they are not familiar with providing services to thousands of disadvantaged patients.

In addition to the above-mentioned problems, the Department of Health (2015a, pp.8, 9) listed a number of challenges in 2015 that are experienced when providing rehabilitation services (that includes occupational therapy services) with the *Strategy for Disability and Rehabilitation Services in South Africa* document. These challenges include:

**the use of a medical model in the provisioning of rehabilitation services;*

**poor availability of services especially in rural areas;*

**inaccurate referral pathways resulting in poor follow- up rates;*

**transport challenges for patients;*

**the absence of rehabilitation indicators questioning the effectiveness of the service;*

**limited research on the topic; as well as*

**human resource challenges.*

The use of the institution-based medical model in providing services on a PHC level was already criticised before 2015 by Dookie and Singh (2012) and it was supported by Bam *et al.* (2013, p.1) who stated that services are predominantly hospital-based and that it prevents the integrated PHC approach to South Africans. It is evident that very little progress has been made in ensuring that services are accessible to patients on a PHC level.

Over and above these challenges is the fact that working within a PHC setting is not a preferred setting for all occupational therapists. The occupational therapist who is working within PHC is expected to provide a wide variety of services within a single day by treating patients from birth all through to the elderly (Muir 2012, p.509). This implies that the occupational therapist should be competent in a variety of clinical skills and should be able to provide services within the entire domain of occupational therapy (Muir 2012, p.509). This can be challenging and not all occupational therapists feel

comfortable with providing these services. This often leads to the therapist focusing on a single population group rather than providing a comprehensive service (Muir 2012, p.509).

It is evident that the implementation of occupational therapy services within the PHC domain in SA is still in its infancy and undoubtedly calls for further research. As this current study deals with the FSDoH, specific challenges that are experienced by occupational therapists in the Free State will be researched.

2.3.3.1. Challenges faced by Occupational Therapists working within the Free State Department of Health

Occupational therapists working within the PHC domain in the Free State are not exempted from the challenges mentioned before. One of the biggest challenges is the lack of adequate human resources. The South African Health Review 2016 stated that in the public sector of the Free State province, only 67 occupational therapists (within all health care levels) were employed during 2015 with an average of 2.9 occupational therapists per 100 000 population (Gray and Vawda 2016, pp.302, 304). Also, due to financial challenges, the FSDoH experienced a vacancy rate of 21.8% for permanent occupational therapy staff in 2015 and similar trends were noted amongst other rehabilitation professions (Free State Department of Health 2016a, p.139). The high vacancy rate is also challenged as occupational therapists are struggling to find employment in the public sector (Anon 2017a). Furthermore, the occupational therapy *Provincial Sector Report* (Vrey 2017) indicated that 22% of the total occupational therapy workforce within the FSDoH comprise of community service occupational therapists. Adding to this, only 12% of the total occupational therapy workforce is employed at the PHC level where the bulk of the patient population are in need of services (Vrey 2017).

Lehmann (2008, p.174) indicated, already 10 years ago, that very little progress had been made to strengthen human resources for the implementation of PHC. This is also supported by a case study that concluded that there were inadequate staff numbers as well as poor diversity of skills on a PHC level to provide in the need of high numbers of

patients (Draper, Draper and Bresick 2014, p.6). Due to the shortage of staff, and in this case occupational therapists, occupational therapy services are not always rendered and accessible within PHC conflicting with the goals set by the *Primary Health Care Package of SA* (Department of Health 2000b, p.67) as well as the *Free State Rehabilitation Policy Guidelines* (Free State Department of Health n.d., p.2). Another challenge was inadequate financial resources as well as poor management of the limited finances that were available (Draper, Draper and Bresick 2014, p.6).

At the time of the research, the researcher had four years of experience as a production level occupational therapist within the TMHD. The researcher has also experienced that occupational therapists cannot rely solely on national and provincial policies as it very rarely includes the profession and therefore provides very little guidance as to how the service should be managed within the PHC domain. The researcher also experienced that there are a lot of discrepancies in the way occupational therapy services are rendered within in the PHC domain in the FSDoH. Some institutions only provide patients with health promotion while other institutions aim at providing a therapeutic service within the PHC setting. This creates confusion and uncertainty amongst therapists and negatively influences patient care.

The above-mentioned challenges necessitate more research on the implementation of rehabilitation services, specifically occupational therapy services within PHC in the Free State. This is crucial to strengthen health policy development in order to render quality and accessible occupational therapy service. It is further important to acknowledge that policy cannot be properly developed without research (Van Wheel and De Maeseneer 2010, p.2), thus strengthening the need for this current study within the FSDoH.

2.3.4. Conclusion: occupational therapy in Primary Health Care

In conclusion, it is evident that occupational therapy services within the PHC domain in SA, and in particular the Free State, are not yet aligned with global trends within the re-engineering of PHC to ensure a high standard of care as well as accessible services to all. Occupational therapy should form part of the essential services that are rendered within the PHC domain and the profession should therefore align its practices

accordingly. This calls for further research to support the demand of occupational therapists to be included in health policies relating to PHC.

Koverman, Royeen and Stoykov (2017, p.8) indicated that the role of occupational therapy in PHC should be developed on a continuous basis in order to include the occupational therapist as a team member in PHC as well as measuring patient outcomes. This was also supported by Halle *et al.* (2018, p.4) who argued that the unique value of occupational therapy should be clearly articulated. The occupational therapist should, therefore, advocate the role he/she has to play in PHC as well as the potential benefits it can provide to patients (Muir 2012, p.509), (Dahl-popolizio *et al.* 2017, p.8). Muir (2012, p.509) further stated that further research is necessary to validate the therapeutic use of occupations leading to functional outcomes for patients.

Occupational therapists can assist by engaging patients in a variety of activities post-illness or disability. The design of an occupational therapy program specifically for the PHC context in the Free State will be of great value to provide in the need of patients by ensuring that the occupational therapy service is accessible, relevant and feasible. This study, therefore, aims at identifying the factors that will ensure such a program. This study will further contribute to the re-engineering of the occupational therapy service within PHC in the Free State, as it will specifically address the challenges that are faced in the province.

The following section will focus on the stroke population. As one of the population groups who receive occupational therapy within the PHC domain, they are the subject of this study.

2.4. STROKE SURVIVORS WITHIN THE CONTEXT OF PRIMARY HEALTH CARE

The management of chronic diseases is one of the priorities mentioned in *The Primary Health Care Package for South Africa - a set of norms and standards* (Department of Health 2000b, p.73). One of chronic, non-communicable diseases that is highlighted as a priority by the NDoH, is that of stroke. It is noteworthy to mention that non-communicable diseases are the leading cause of mortality and disability globally

(Puoane *et al.* 2017, p.172) and the prevalence of non-communicable diseases are rising in SA (Department of Health 2015b, p.20). One of the NDoH's visions for 2030 includes the reduction of the prevalence of non-communicable diseases drastically in SA (Department of Health 2015b, p.21). With the focus on non-communicable diseases, and stroke forming part of these diseases, the following section will provide more insight into the pathology. This section will also inform the reader on the role that the occupational therapist has to play in the management of stroke survivors as well as the challenges that stroke survivors are experiencing. This will inform the reader of the importance and the need for the development of an occupational therapy stroke program that can be offered to patients on a PHC level.

The following section will specifically focus on stroke survivors within the TMHD. The TMHD is a health district of the FSDoH and it was also the district of interest for this research. By focussing on the TMHD, the reader will be provided with an in-depth understanding of the district, the burden of disease as well as unique challenges.

2.4.1. Stroke pathology and management

The WHO defines a stroke as an “... *interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot, causing damage to brain tissue*” (World Health Organization 2018c). Strokes can be classified into two main types, namely: ischemic and haemorrhagic. Ischemic strokes are caused by insufficient blood flow to the brain that may be the result of an embolism in the brain (Gillen 2013, p.846). A haemorrhagic stroke is caused by haemorrhage (blood flow) to the brain that can be either subarachnoid or inter-cerebral (Gillen 2013, p.846). Not only does a stroke cause damage to brain tissue, but it also affects and may cause dysfunctions and disabilities in a person's motor functioning, cognitive, perceptual, sensory and visual areas as well as to the person's speech and communication abilities (Gillen 2013, p.846).

The WHO indicated that 6.6 million deaths occurred globally due to stroke during 2012 (World Health Organization 2016). Not only is it a concern that stroke is causing death and disability globally, but it is also a major concern in SA. *The South African guideline*

for management of ischemic stroke and transient ischemic attack, indicated that one of the main causes of death and disability in SA is stroke (Bryer *et al.* 2010, p.750).

It was found that stroke was the fourth leading cause of death in SA during 2016 (Statistics South Africa 2018, p.32) under the category of natural deaths. When looking at the cause of death by sex, stroke is the second leading cause of natural deaths amongst women and ranked sixth amongst males in SA (Statistics South Africa 2018, p.33). In the Free State, stroke was the fourth leading cause of natural deaths during 2016 (Statistics South Africa 2018, p.42). Furthermore, stroke was ranked the fifth leading cause of natural deaths in the TMHD during 2016 (Statistics South Africa 2018, p.130).

As mentioned, a stroke can cause a number of disabilities. Stroke is the ninth leading cause of disabilities in SA (Bryer *et al.* 2010, p.755) but accurate data on specific disabilities due to stroke is scares (Maredza, Bertram and Tollmann 2015, p.10). In a study done by the South African Stroke Prevention Institute (SASPI), it was found that SA has a high number of stroke incidence as well as a high number of stroke survivors living with disabilities (Connor *et al.* 2004, p.630). This study was, however, done more than ten years ago and no recent information is available on the prevalence of disabilities due to stroke.

As stroke can cause a variety of disabilities, it is of vital importance that stroke survivors have access to medical and rehabilitative services. Bryer *et al.* (2010, p.762) recommended that acute ischemic strokes should be treated as a medical emergency and immediate medical attention should be offered to these patients. After medical treatment has been offered and the patient has been stabilized, stroke rehabilitation can commence. The goal of stroke rehabilitation is to attempt to regain lost functions and to enable patients to return to their families and the community life by addressing the physical, cognitive and language barriers they experience following the stroke (Bryer *et al.* 2010, p.775).

The *South African Guideline on stroke management* further prescribes that rehabilitation will commence in the hospital or stroke unit and will continue on an outpatient basis

when the patient is discharged for a period of one year after the stroke (Bryer *et al.* 2010, pp.775, 776, 778). Bryer *et al.* (2010, pp.775, 776) also stated that inpatient therapy is advisable as better outcomes are achieved than on an outpatient basis. When considering rehabilitation services, the occupational therapist has a distinct role to play in the management of stroke survivors. Lovat *et al.* (2010, pp.171, 172) indicated that one of the outcomes of occupational therapy should be to support the family members and the caregivers of stroke survivor by providing adequate health information and actively involving caregivers and family in therapy interventions. Apart from the support that the occupational therapist can provide to the family, a range of other therapeutic services can also be provided and will henceforth be discussed.

Gillen 2013 (pp.852, 853) suggests that the occupational therapist should take on a client-centred approach when evaluating and treating the stroke survivor, specifically within the hospital setting. A number of standardized assessment tools are available to evaluate the performance in all areas of occupation. Woodson 2008 (pp.1012–1021) indicated that occupational performance is assessed by evaluating the stroke survivor's participation in activities of daily living as well as assessing their component abilities and capacities that include postural adaptation, upper extremity function, strength and endurance, motor learning ability, visual function, speech and language, motor planning and cognitive abilities. Once the assessment has been completed, a framework for intervention can be developed.

The goal of occupational therapy intervention is to allow the stroke survivor to resume meaningful roles by making use of functional activities as a task-orientated approach (Gillen 2013, p.855). Woodson 2008 (p.1022) provides insight into the occupational therapeutic treatment guidelines for stroke survivors and will be discussed according to three phases, namely: the acute phase, rehabilitation phase and the transition into the community.

During the acute phase (initial admission to the hospital) the stroke survivor can commence with rehabilitation as soon as it is medically feasible. During the acute phase, occupational therapy rehabilitation will focus on early mobilization, return to self-

care and the prevention of secondary complications by maintaining soft tissue length and giving family and patient education on skin care and fall prevention (Woodson 2008, pp.1022, 1023).

During the rehabilitation phase, the stroke survivor is discharged from the acute medical ward and rehabilitation can be continued at an inpatient rehabilitation centre or on an outpatient basis (Gillen 2013, p.1024). Treatment during the rehabilitation phase will focus on the improvement in the performance of occupational tasks by teaching compensatory methods and providing adaptive devices to participate in activities in daily living. Treatment will further focus on postural control and adaptation as well as upper extremity function and component abilities as mentioned before (Gillen 2013, pp.1025, 1030, 1031).

During the transition to the community phase, the occupational therapist will not be as closely involved with the stroke survivor any longer, as the stroke survivor should now feel capable of continuing progress and maintaining his/her level of functioning (Gillen 2013, p.1031). This phase is accompanied by training that will be given to the family and caregiver on essential skills that is needed to take care of the patient. During this phase, the occupational therapist will assist the family in reintegrating the survivor into the home and work environment (Gillen 2013, p.1032).

From the above information, it is evident that the valued role of the occupational therapist in assisting the patient to engage in activities of daily living as well as reintegrate into the community, can be underestimated. The occupational therapist plays an important role in the recovery of the stroke patient and therefore the following section will focus specifically on occupational therapy services to stroke survivors within the context of the TMHD.

2.4.2. Occupational therapy services to stroke survivors within Primary Health Care in the Thabo-Mofutsanyana Health District

As mentioned previously, stroke survivors are faced with a number of disabilities that may occur in their cognitive, motor, sensory and visual functions. The Free State,

together with the Northern Cape, are the two provinces with the highest number of people living with disabilities with a prevalence of 11% in comparison with the national prevalence of 7.5% (Department of Health 2015a, p.6). As the TMHD is located within the Free State, a high number of people with disabilities require health care.

As mentioned before, strokes are one of the top ten causes of natural deaths and it is, furthermore, one of the top ten non-communicable diseases in the TMHD. Stroke survivors receive several health care interventions, including occupational therapy treatment. During 2017 eleven occupational therapists have seen 629 stroke survivors in the TMDH (Free State Department of Health 2017). From 2016 to 2017, an increase of 4% was noted in the number of stroke contact sessions, however, there has been a decline in the number of occupational therapists working in the TMHD (Free State Department of Health 2016b). The researcher established that the decline in the number of occupational therapists is due to the limitation of appointing new permanent staff as well as inconsistencies in the availability of community service occupational therapists (cf. 2.3.3.1).

All the occupational therapists in the TMHD are employed at district hospitals. There are thus no occupational therapists specifically designated to provide services to patients on a PHC level. In the TMHD the outreach model is commonly applied where therapists from the district hospitals visit the PHC clinics to provide occupational therapy services. However, there is currently no information available on the methods of practice or the effectiveness of occupational therapy services to PHC.

As there are no therapists formally assigned to serve the PHC clinics, the accessibility of occupational therapy services on a PHC level in the TMHD is questionable. A study in another province in SA found that patients burdened by non-communicable diseases and disability have poor access to rehabilitation services (Draper, Draper and Bresick 2014, p.4). Although this study cannot be generalized to the TMHD due to differences in geography and context, the research has experienced that a similar trend can be observed in the TMHD. This is problematic when considering the aims that the NDoH seek to achieve through the implementation of PHC services in SA. The NDoH's

Performance Plan indicates that disabilities of patients with non-communicable diseases should be managed and that rehabilitation services should be strengthened (Department of Health 2017a, p.51). This is supported by the *National Forum for occupational therapy in the Public Sector* that indicates that one of the main goals is to integrate disability and rehabilitation services within the domain for non-communicable diseases, including stroke survivors (Anon 2017b).

It is evident that research is needed to establish whether the above-mentioned goals are reached as well as to explore ways of overcoming the barriers to achieve these goals. Without a doubt, a call is made to investigate the current practices of occupational therapy service delivery to stroke survivors within the TMHD. Research will allow the researcher to have a clearer understanding of the needs and the context of the stroke survivors within the TMHD and this information is especially important when considering factors that will influence the designing of an occupational therapy stroke program that will be relevant and feasible for the PHC domain. It is however not only important to focus on occupational therapy, but the challenges faced by the stroke survivor should also be considered.

2.4.3. Challenges faced by stroke survivors who seek occupational therapy services within Primary Health Care

The previous section focused on an occupational therapy perspective to stroke rehabilitation. This section will be focussing on the stroke survivor's point of view. Stroke patients experience a variety of challenges when seeking rehabilitation, and in particular, occupational therapy services. Cawood and Visagie (2016, pp.24, 25) found that stroke patients in an urban setting in the Western Cape experienced a number of challenges in accessing rehabilitation services, including occupational therapy services. These challenges included the cost of transport, inaccessibility of transport for wheelchairs and the weakness of patients to attending therapy sessions. In unpublished work, Mapipa (2014, p.10), also found that patients often did not adhere to their rehabilitation program due to transport difficulties, insufficient frequency of therapy sessions as well as a lack of knowledge regarding their condition and the treatment

required. Challenges regarding transport were further emphasized in a study conducted in Johannesburg, South Africa, where 100% of the participants indicated that they have experienced transport as a barrier to attend rehabilitation services (Mudzi, Steward and Musenge 2013, p.7).

Although transport is not the only challenge that stroke patients experience, it has a direct impact on the health outcomes of stroke survivors. McLaren, Ardington and Leibbrandt (2014) found that patients experienced a burden due to the long distances they had to travel to healthcare facilities. In SA 90% of patients have to travel up to seven kilometres to their nearest public healthcare facility (McLaren, Ardington and Leibbrandt 2014). They also found that it is more likely that the poorest income quintiles live farther away from the nearest PHC clinic. The study further concluded that the choice for patients to seek health care directly links with the cost of travelling to the health care facility (McLaren, Ardington and Leibbrandt 2014).

Stroke survivors are however not only experiencing challenges to access therapy, but challenges are also experienced regarding their physical functioning and community integration. Mudzi, Steward and Musenge (2013, pp.6, 7) investigated the factors that influences a patient's ability to participate in his/her community post-stroke and found that walking ability, lifting and carrying of objects, preparing meals, doing housework, interpersonal relationships, recreation and leisure ability were all negatively influenced. Stroke survivors further experienced barriers due to the unavailability of proper housing to accommodate their disabilities as well as difficulties in obtaining social grants (Mudzi, Steward and Musenge 2013, p.7).

These factors, mentioned above, are negatively influencing the stroke population. After a systematic review on stroke survivors' experience of primary care, Pindus *et al.* (2018, p.14) asserts that the stroke population is marginalized due to a number of factors that include the lack of continuity of care, the lack of follow-up, limited or delayed access to community services as well as inadequate information regarding stroke pathology. Stroke survivors further do not have the necessary skills and knowledge to reintegrate into their previous level of functioning and therefore it is of utmost importance to ensure

that stroke survivors receive stroke-specific health education as well as proper access to community healthcare services (Pindus *et al.* 2018, pp.14, 15).

Another challenge facing stroke survivors is that of accessing rehabilitation services. Bryer *et al.* (2010, pp.775, 776) stated that inpatient therapy is advisable as better outcomes are achieved than on an outpatient basis. However, this ideal is not always possible and it is further challenged by the shortage of stroke units in the public healthcare sector in SA (Bryer *et al.* 2010, p.775). Rhoda *et al.* (2015, p.7) further added that stroke survivors are not admitted to a hospital to receive rehabilitation services, but rather to receive medical attention until they are stable where after they are discharged. This poses a challenge for rehabilitation officials as inpatient contact with stroke survivors are limited and they are discharged without being at a satisfactory level of functioning. The short length of stay is further not allowing them to receive adequate rehabilitative and occupational therapy care as they are not offered the opportunity to learn compensatory methods and proper modification of limitations and above that, family members or caregivers are not provided with the necessary training and education (Cawood and Visagie 2016, p.25).

In addition, stroke survivors are not always followed up in their communities, which is a great cause of concern for therapists as it leads to minimal therapeutic interventions leading to a poorer health outcome (Rhoda *et al.* 2015, p.7). Joseph *et al.* (2017, p.5) advocate that stroke survivors must receive outpatient rehabilitation services as soon as possible after being discharged from hospital and this is supported by Mudzi, Steward and Musenge (2013, p.9) who also stresses post-stroke rehabilitation services. Mudzi, Steward and Musenge (2013, p.9) indicated that post-stroke rehabilitation services should address community participation and this aspect specifically relates to the occupational therapist when considering the aspect of context and environment within the OTPF (discussed under 2.3.1). The above-mentioned challenges demonstrate the need for further research in order to address the gaps that are being experienced as well as to improve accessibility to rehabilitative services for stroke patients.

Rhoda *et al.* (2015, p.4-6) identified another challenge by indicating that stroke survivors feel socially isolated; they are unable to participate in usual activities as well as leisure activities; they are unable to fulfil their roles as they used to prior to the stroke (role restriction); their health status deteriorated significantly; the lack of physical recovery causes feelings of uselessness; they are also experiencing a lack of social support from significant others and their physical environments are a barrier to their mobilization and participation in the community. Cawood, Visagie and Mij (2016, p.14), however, argued that it is not only physical limitations that restrain activity participation. They found that activity participation is also negatively influenced by perceptual and cognitive skills that includes visual and spatial perception, thinking skills and motor apraxia and that these aspects are crucial and should be addressed in therapy.

From this information, it is evident that the stroke survivors in South Africa are burdened with a variety of difficulties when seeking health care, especially within the PHC domain. Strasser (2003, p.458) already indicated in 2003 that SA is burdened with poverty as well as low health status and that healthcare provision should be improved for people living in rural areas. This reinforces the need to identify factors that will influence the design of an occupational therapy stroke program to ensure that all the aforementioned challenges will be addressed and aiming at the improvement of the quality of life of stroke survivors.

2.4.4. Conclusion: Stroke survivors within the context of Primary Health Care

This section on stroke survivors within the PHC context has made it clear that stroke survivors are not only burdened by their post-stroke experiences, but access to health care, in particular occupational therapy services, is inadequate. This curtails their quality of life and it prevents them from re-integrating into their communities effectively. Stroke survivors should, therefore, be provided with easy access to rehabilitation services, and in the context of this study specifically, occupational therapy services, in order to address occupational dysfunction following a stroke. After a study in the Western Cape, Cawood and Visagie (2016, p.26) strongly recommended the provisioning of occupational therapy sessions for stroke patients as well as improving the accessibility

to occupational therapy rehabilitation services. They also exhort the strengthening of human resources for occupational therapy to foster better health outcomes for stroke patients. In order to achieve these goals in the Free State, more research should be done on the current status of occupational therapy service provision to stroke patients within PHC.

2.5. CONCLUSION

This chapter sought to provide the reader with an overview of the context as well as the points of reference that forms the basis for this research project. The chapter commenced with a global perspective on PHC and how it developed throughout the years. As SA aligns its health practices with those of the WHO, the PHC in SA and how these practices are transforming by means of re-engineering was investigated. The re-engineering of PHC services refers to the strengthening of all health service elements within the PHC domain that includes the DHS, WBOT as well as the DBST. The re-engineering of health care in SA, however, involves all practitioners and without a doubt also includes the rehabilitation worker. The functioning and purpose of PHC within the newly proposed NHI in SA was investigated as this will have relevance in the near future.

The true essence of this study, however, revolves around the profession of occupational therapy and the patients that are served. The roles of the occupational therapist within PHC were explored and ways to re-engineer the profession were identified. It is clear that practising occupational therapy within PHC can be challenging and that creative and innovative ideas to improve health care service delivery are essential.

Occupational therapists are furthermore passionate about providing their patients with the opportunity to engage in activities as well as providing them with the opportunity to reintegrate into their communities. This is also true for stroke survivors. Stroke survivors are one of the biggest patient populations that are seen by occupational therapists in the TMHD. Stroke burdens these patients with a number of challenges and the role of the occupational therapist cannot be overemphasized. These patients do not only suffer physical disabilities; they are also facing a number of other challenges that prevent

them from accessing occupational therapy services.

This chapter, therefore, emphasizes the need to explore the way in which occupational therapy services are provided to stroke patients and how these services can be re-engineered to ensure that the patients can access the services, but equally important, to ensure their optimal level of functioning and reintegration into their communities. The designing of an occupational therapy program for stroke survivors within the PHC domain will aim at ensuring that stroke survivors reach their optimal level of functioning. Therefore, this study will focus on the factors that will influence the design of such a program to ensure that it is relevant and feasible within the PHC context, taking into consideration all of the challenges as well as the opportunities at hand.

With this research study, the researcher aims at exploring the current methods of occupational therapy service delivery within the TMHD with specific relevance to the PHC domain. The researcher also aims at establishing the challenges that are hindering the successful integration of occupational therapy into PHC. With the results of this study the researcher aims at making occupational therapy services relevant and available to stroke survivors within their immediate environment. Adding to these aims, the researcher also aims to strengthen the knowledge base of occupational therapy services and practice within PHC, especially within the TMHD in the Free State.

Chapter three will, henceforth, present information on the methodology that was utilized to investigate the above-mentioned aspects by describing how the DSR study design was implemented for this study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1. INTRODUCTION

Chapter 2 provided the theoretical background that underlies this study. It also served as motivation for the need to research occupational therapy practices within PHC in the TMHD with the aim of identifying the factors that will ensure the design of a relevant and feasible occupational therapy program for stroke survivors. This chapter will provide information on the research process that was implemented to answer the research question stated in Chapter 1.

This chapter will, therefore, discuss the paradigm this research study was positioned in, as well as the method of inquiry used by elaborating on the study design and research methods. As mentioned in Chapter 1, the research included a series of data collection activities and each activity will be described according to its data collection methods, management and analysis of data. This chapter will furthermore discuss the validity and reliability of the data collected, trustworthiness, errors in data collection as well as the ethical considerations pertinent to the study.

As mentioned in Chapter 1, a DSR methodology was used. This study focused only on phase one of the DSR methodology and phases two and three may be considered for future research projects. The execution of phase one of the DSR methodology, will henceforth be discussed.

3.2. RESEARCH PARADIGM

Barker (2003, p.312), as cited in De Vos, Strydom and Delport (2011, p.513), defined a paradigm as "... a pattern containing a set of legitimated assumptions and a design for collecting and interpreting data." A paradigm thus forms the basis of scientific research (De Vos, Stydom and Delport 2011, p.513) and it predicts how the data for research can be collected and interpreted. In order to answer the research question and identify the factors that will ensure the designing of a relevant and feasible occupational therapy program, this study is positioned within a pragmatic worldview. Teddlie and Tashakkori (2009), as cited in De Vos, Strydom and Delport (2011, p.438), describes pragmatism

as "... a deconstructive paradigm that debunks concepts such as 'truth' and 'reality' and focuses instead on 'what works' as the truth regarding the research question under investigation." Goldkuhl (2004, pp.21, 22) further added that a pragmatist is concerned with "... what works and how and why it works."

In this study, the researcher was not only interested in "what" the factors were that could influence the relevance and feasibility in the design of an occupational therapy program for stroke survivors, but the researcher was also interested in "how" these factors could influence the design of such a program in order to be successfully implemented. From a pragmatic worldview the researcher was thus not only interested in interpretive descriptions during the research process, but also had an interest in action and practice, as described by Goldkuhl (2004, pp.21, 22). The researcher, therefore, wanted to explore all the factors influencing the current practice of occupational therapy service delivery within the PHC setting as this will ensure the design of a relevant and feasible occupational therapy stroke program.

With the researcher's worldview grounded in pragmatism, a suitable study design had to be selected in order to address all of the questions raised above. Neither a pure qualitative nor a quantitative study method was apt to answer the research question at hand. A mixed-method study design was then considered, but it was still clear that it would not fully support the researcher in addressing the aims of this study. The researcher was then introduced to DSR and it was evident that DSR as a study design had the potential to answer the research question at hand as well as to address the aims of this study.

DSR is, however, not only a study design, but it is also a research approach. The researcher further chose DSR as a research approach for this study as it is eloquently aligned with the pragmatic paradigm. Vaishnavi and Kuechler (2004) also describe the design science researcher as a pragmatist while Offermann *et al.* (2009, p.2) and Hevner *et al.* (2004, p.78) added that DSR attempts to bridge science and practical action. This is supported by Howie (2016, p.4) who stated that the purpose of design research is to improve practice and contribute to the body of knowledge. With these

elements of DSR taken into consideration, it was clear that the use of DSR as a research approach (and study design) would provide the researcher with a practical and effective way of answering the research question. The implementation of DSR enabled the researcher to contribute to the current body of knowledge regarding occupational therapy practices for stroke survivors within the PHC context. This was achieved through the identification of specific treatment approaches and methods that are applied within this context.

As DSR was chosen as a study design, it will now be described according to its axiology, ontology and epistemology:

Axiology: Vaishnavi and Kuechler (2004, p.14) defines axiology as the study of values and described the axiology of DSR as the quest for truth, understanding as well as creative manipulation. In this study understanding the various factors that would influence the design of an occupational therapy stroke program as well as understanding how these factors could contribute, and/or be adapted and/or utilized in the design process to ensure an improved health outcome for stroke survivors, was necessary. This information is essential for this study as it will ensure that the programs that will be designed in future studies, will be feasible and effective for the specific target population.

Ontology: Vaishnavi and Kuechler (2004, p.14) define ontology as the "...study that describes the nature of reality". Polit and Hungler (2008), as cited in Botma *et al.* (2015, p.40), stated that ontology deals "... with how we view the world." As this study is positioned within a pragmatic worldview, pragmatism is the primary ontological position of the study. Vaishnavi and Kuechler (2004) acknowledge that the design science researcher is situated in multiple, but contextual world-states. For the purpose of this study, the researcher will explore the different views of all of the stakeholders in the PHC setting who are involved (directly and indirectly) in the rendering of occupational therapy services to stroke survivors. The exploration of the multiple views of all stakeholders will better inform the researcher on the factors that need to be considered when designing an occupational therapy stroke program for the PHC context.

Epistemology: Vaishnavi and Kuechler (2004, p.14) define epistemology as the study that "... explores the nature of knowledge." Epistemology thus deals with how knowledge is created. Vaishnavi and Kuechler (2004) further state that information is viewed as factual by the researcher and that meaning is given to that information through construction. Knowledge is therefore retrieved throughout the design process. For the purpose of this study, a knowledge base regarding the current status of occupational therapy service delivery within PHC in the TMHD as well as the factors that need to be considered for the design of a successful program was gathered. Not only will this knowledge base contribute to the current body of knowledge on occupational therapy within PHC, but it will provide a platform for future studies. However, the researcher acknowledges that the knowledge built is subjective and is provided within a specific context.

With this study based on a pragmatic worldview, the following section will provide the reader with information on how the DSR paradigm and study design was applied to gather the data that was required to answer the research question and to identify the prevailing factors that will be influencing the design of an occupational therapy stroke program for the PHC context. These factors relate specifically to the structural, procedural and challenge factors that will influence such a program.

3.3. THEORETICAL OVERVIEW OF THE DESIGN SCIENCE RESEARCH STUDY DESIGN

This section elaborates on the application of the DSR methodology for this study in terms of the DSR process that includes three phases, namely: problem identification, solution design and evaluation (Offermann *et al.* 2009, pp.4–6). The DSR study design allowed the researcher to involve multiple stakeholders who are servicing stroke survivors on a PHC level within the TMHD in order to optimally address the aims of the study. The researcher thus ensured that the factors identified will be relevant and feasible.

Design-based research is defined as "... a series of approaches, with the intent of producing new theories, artefacts, and practices" (Barab and Squire 2004, p.2), (Van

den Akker *et al.* 2006, pp.4, 5). A problem-orientated approach is therefore followed within design science (Raptis *et al.* 2012, p.23) and Hevner *et al.* (2004, p.82) added that the building of an artefact constitutes the knowledge base and understanding of a design process, forming the fundamental principle of DSR. The current study will form the basis from which an artefact will be designed in the future, namely an occupational therapy stroke program for the PHC setting. The current study focused on the factors that will influence such a program, therefore contributing to the understanding of the design process that is still to follow.

Various descriptions are found to illustrate the process of DSR (Offermann *et al.* 2009, p.3, Van den Akker *et al.* 2006, p.47, Nieveen 2009, p.15). Offermann *et al.* (2009, p.3) divides the DSR process into three main phases (problem identification, solution design and evaluation) that are further divided into sub-aims, during which both qualitative and quantitative research methods are utilized. Van den Akker *et al.* (2006, p.47) also describes three phases, but define them differently, namely: preparing for the design experiment, design experiment and retrospective analysis. Another description is given by Plomp (2007, p.15) who stipulates the three phases as preliminary research, the development/prototyping phase and the assessment phase. The principles underlying these three main phases are basically the same and for the purpose of this study the description and terminology proposed by Offermann *et al.* (2009, pp.4–6) will henceforth be discussed.

3.3.1. Design Science Research Process

The three phases or processes, as mentioned above, will be elaborated on and detailed information will be given on what can be expected from each phase of the study.

a) Problem identification

The first step when starting the research is to identify the problem. In DSR the problem identification phase is divided into three sub-aims (Offermann *et al.* 2009, pp.4, 5):

Identify problem: During this phase a relevant problem needs to be identified that will be of interest to all the stakeholders involved. Howie (2016, p.6) adds that a needs analysis needs to be executed to identify the problem.

Literature research: A thorough literature review is needed to delineate the problem that will be researched as well as to inform the researcher on the current status of the problem and obstacles that can be expected along the way.

Expert interviews: Interviews needs to be conducted with experts within the field that will be analysed in order to obtain information pertaining to the identified problem as well as to inform and design possible solutions.

During this phase, relevance should be emphasised (Howie 2016, p.12). The knowledge and information gathered in this phase are used to inform the researcher on the relevance and feasibility of the artefact that will be designed in the second phase.

b) Solution Design

The second phase in the research process is defined as the solution design. This phase is again divided into two activities, namely: artefact design and a supportive literature research (Offermann *et al.* 2009, p.5). During this phase, also named the iterative design phase or prototyping phase, as stated by Howie (2016, pp.6, 12), a iterative process of formative evaluation will be used to ensure that the artefact is evaluated and revised to ensure its practicality and effectiveness (Howie 2016, pp.11, 12). This indicates that more than one prototype will be developed and evaluated in order to design the selected artefact.

Design artefact: During this phase, an artefact is designed to address the problem identified during phase one of the research process. Hevner et al. (2004, p.83) stated that an artefact can be presented in different forms. This includes either a construct, a model, or a method or instantiation. Howie (2016, p.3) added that the intervention designed can also include a programme, process, product or system.

Literature Research: Ongoing literature research is necessary to support the research rigor and to allow the inclusion of updated scientific information (Offermann *et al.* 2009, p.5).

c) Evaluation

The last step in the research process is the evaluation of the artefact to ensure its practicality and relevance (Howie 2016, p.12).

Van den Akker *et al.* (2006, p.5) adds that DSR has some unique characteristics that include the designing of an intervention fit for a real world setting; that practitioners are actively involved throughout all stages of the research; that the practicality of the design is measured in real contexts and that the process further adds to theory development.

The DSR study design, therefore, offers a unique and practical method to address the problems that the researcher is facing within the PHC domain. It grants the incorporation of various data collection activities as both qualitative and quantitative methods may be utilized and incorporated. It further allows the researcher to explore and offer solutions for real world problems and simultaneously add to the knowledge base of occupational therapy practices within PHC.

3.4. OPERATIONALIZATION OF THE DESIGN SCIENCE RESEARCH STUDY METHOD IN THE CURRENT STUDY

Only the first phase of the DSR process will be implemented for the purpose of this master's level study (cf. 1.7.). Phase one of the DSR process has been divided into five activities for the purpose of this study. A graphical presentation of the composition of this study can be seen in Figure 3.1. The figure, however, includes all three phases of the DSR study design in order to provide a holistic representation of how this study can be utilized as a basis for future studies.

Figure 3.1 provided an overview of the DSR process that was followed for the current study, as well as the proposed activities for future studies. The figure includes the five activities that were executed to answer the research question and meet the objectives

Process to conduct a design science research methodology to identify the factors that will influence the design of an occupational therapy stroke program in PHC

CURRENT STUDY

Phase 1:

Problem identification and establishing relevance

Activity 1: Literature review including document review



Activity 2: Structured observation of PHC facilities



Activity 3: Structured interview with CHW's



Activity 4: Focus group with occupational therapists working with stroke survivors in the PHC setting



Activity 5: Semi-structured interviews with stroke survivors who received OT services within the PHC setting

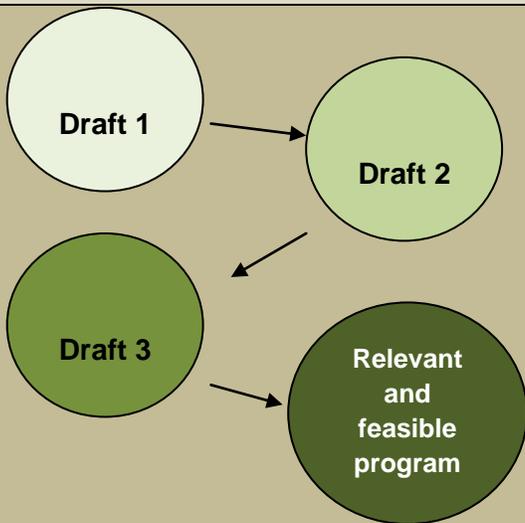


Compiling document with factors that will influence the design of an OT stroke program for PHC

FUTURE STUDIES

Phase 2:

Solution Design



Draft	Action
1	The factors identified during phase 1 will be used to design an OT program for stroke patients. This will be called draft 1. The draft will then be discussed and evaluated by various stakeholders and adaptations will be made. The process will continue until an implementable program is designed.
2	
3	
Implementable program for stroke patients	

Phase 3:

Evaluation

Evaluation of the artefact that was designed. Evaluation will be done and adaptations will be made where gaps are identified.

During the process of designing, a base of knowledge will also be gathered to contribute to the current body of knowledge on occupational therapy service delivery to stroke survivors within the PHC setting.

Figure 3.1: Research Process (Developed by the researcher)

of this study. The various activities each met at least one, or more, of the set objectives. The section on the operationalization of the DSR method for the current study will henceforth be discussed. The research context will be provided, thereafter, each activity will be presented individually. For each activity the data collection and data management will be described and this section will be concluded with a summary of all the activities.

3.4.1. Research context

As mentioned in both Chapters 1 and 2, this study was conducted within the TMHD. The TMHD is a sub-district of the FSDoH, where the researcher has been employed at for four years in a production level post, during the execution of the study. The researcher was thus familiar with the dynamics, strengths and weakness of the occupational therapy services in the district. The data collected will not only be used to support the researcher in achieving the aim of this study, but it will also be used to form a basis of scientific knowledge regarding occupational therapy practices within PHC for stroke survivors. The data were used to identify the factors that would influence the design of relevant and feasible stroke program.

As the DSR method allows for the inclusion of multiple stakeholders, the researcher included various key stakeholders who are involved in rendering services to stroke survivors within the TMDH on a PHC level. PHC refers to the first level of services that a patient will receive when entering the health system and refers to District Hospitals, PHC Clinics and can also include outreach visits to different community institutions (Free State Department of Health n.d., p.12). Firstly, this study has focused on the occupational therapy services that are rendered to stroke survivors at PHC level within the TMHD. The TMHD is divided into six sub-districts. At the time of the execution (2017) of this study, there were seven permanently employed occupational therapists (including the researcher) based at six District Hospitals within the TMHD. There is currently (2019), however, only six permanently employed occupational therapists in the district. The occupational therapists from the six District Hospitals are required to conduct all of the outreach services to PHC clinics and community institutions within the

TMHD to ensure that all patients (not only stroke survivors) in need of occupational therapy services are attended to. with the respective sub-districts and it indicates the PHC clinics and district hospitals for each sub-district.

Table 3.1 indicates the distribution of the six permanently employed occupational therapists within the district (compiled by the researcher).

Table 3.1: Distribution of permanent occupational therapists within the Thabo Mofutsanyana Health District				
Sub Districts of the TMHD	Number of District Hospitals	Number of PHC Clinics	Number of permanently employed occupational therapists	Number of community health service occupational therapists
Mantsopa	1	9	0	0
Setsotho	3	11	3	1
Nketoana	1	6	0	0
Dihlabeng	1	9	2	1
Maluti-a-pofung	2	33	1	2
Phumelela	1	5	0	1

Due to the lack of a sufficient number of permanent occupational therapy staff, as is evident from Table 3.1, as well as the inconsistency in the placement of community service occupational therapists allocated to the District Hospitals annually, the capacity of the therapists to render services is limited. The researcher has experienced that a great need exists for new working structures and therapeutic interventions to allow patients to be serviced more efficiently and effectively within the current human resource constraints.

The stroke survivors who are in need of occupational therapy services within the TMHD, range from very young to the elderly. The majority of the stroke survivors are living in rural areas where running water and electricity is not always a given. Most stroke survivors live in dire poverty. Often, stroke survivors are not employed, and very few stroke survivors had been employed prior to their stroke. Accessing health care is therefore also a challenge, as stroke survivors often need to pay unrealistic transportation fees in order to access a PHC clinic or a district hospital. Furthermore, occupational therapy services are also not always readily available, which further limits the health outcomes for stroke survivors.

In order to meet the needs of both the therapists and the stroke survivors and to address these problems, the researcher has included various stakeholders in the study due to their immediate contextual significance, as suggested by Mouton and Marais (1996:133), as cited in Botma *et al.* (2015, p.195). The researcher has therefore not only included the occupational therapists in this study, but also other members (CHWs) of the multi-disciplinary team working within the TMHD. The researcher furthermore included stroke survivors to gain insight into their experiences of receiving occupational therapy services as well as their perspectives on pertinent considerations for occupational therapy services to stroke survivors. Apart from involving these stakeholders, the researcher also visited PHC clinics within the TMHD to determine the structural setting from which services are rendered to stroke survivors. This provided the researcher with the opportunity to gain an in-depth understanding of the context, strengths and weaknesses of current occupational therapy services in the TMHD. The different activities were used as a guideline to identify the factors that will be essential in the designing of an occupational therapy program for stroke survivors.

The following section will describe each of the activities (as mentioned in Figure 3.1) that were implemented during this research study together with its data collection, management and analysis.

3.4.2. ACTIVITY 1: DOCUMENT REVIEW

During activity 1 (cf. Figure 3.1) a literature search was completed to inform the researcher on the current body of knowledge available that could influence the identification of factors for an occupational therapy program for stroke survivors. The literature search was then used to compile a document analysis. The purpose of this was to inform the researcher on the information available to support occupational therapy services within the PHC domain and specifically within the TMHD. The information that was collected, related specifically to the FSDoH as it is the governmental health department relevant to this study. The document analysis aimed at addressing objective one and five for this research study, namely to describe:

- The structural factors regarding the relevance of the current regulatory documents within the TMHD on the provisioning of occupational therapy services to stroke patients within the PHC setting.
- The challenges that stroke patients experienced while receiving occupational therapy services within a PHC setting (from the perspective of the health system) through information included in the relevant policies and legislation.

The research process for the document analysis will henceforth be discussed.

3.4.2.1. Data Collection

The researcher identified a number of documents that specifically relate to public health care within the TMHD in the FSDoH. These documents were selected according to its relevance towards one or more of the following inclusion criteria, namely documents:

- addressing the re-engineering of PHC services in TMHD, and/or
- addressing the re-engineering of occupational therapy services within PHC, and/or
- relating to the rendering of occupational therapy services within the TMHD and/or the FSDoH, and/or
- including information regarding financial aspects of occupational therapy service delivery within PHC in the FSDoH

Documents that did not relate to any of the criteria mentioned above, were excluded.

The researcher identified the documents by executing a literature search and scrutinizing all of the documents that could be found on the websites of the National Department of Health as well as the Free State Department of Health. The researcher ascertained whether the documents met the inclusion criteria or not. Only those that met the inclusion criteria were included in the document review. The documents included in the review are as follows:

1. Free State Department of Health Strategic Plan 2015/16-2019/20 (Free State Department of Health 2015b)
2. Free State Department of Health Annual Report 2015/2016 (Free State Department of Health 2016a)
3. Free State Thabo Mofutsanyana District Report (Health System Trust n.d.)
4. Thabo Mofutsanyana Service Transformation Plan (Free State Department of Health 2014)
5. Free State Department of Health Rehabilitation Policy guidelines (Free State Department of Health n.d.)
6. Free State Department of Health Occupational Therapy policy draft (Free State Department of Health 2013)
7. District Health Plan 2016/2017 (Free State Department of Health 2015a)
8. The Primary Health Care Package for South Africa - a set of norms and standards (Department of Health 2000b)
9. Community Operation Manual (Beukes et al. 2006)
10. Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020 (Department of Health 2015a)

11. National Rehabilitation Policy (Department of Health 2000a)

After the documents had been identified, the public documentations were reviewed and only the documents that met the inclusion criteria, was reviewed. Where no documents could be found that relates specifically to the TMHD, provincial or national documents were used. The researcher compiled a summary of the findings by making use of a data extraction table. The data extraction table was designed by the researcher with elements, identified during the literature search in Chapter 2, that specifically describes the functioning of occupational therapy services within the PHC setting. These elements were categorized according to the objectives of this study (cf. Annexure C). The following section will provide more information regarding the management of the data extraction table and the document review.

3.4.2.2. Data Management

The document review was compiled by making use of a data extraction table (Annexure C). The data extraction table included two sets of data. Firstly, the data that the researcher were looking for, and secondly, the data that was found in the literature and documents. For each document or literature piece, the table was completed according to the two sets of data that were required.

Botma *et al.* (2010, p.87) indicate that triangulation has the aim of gaining a multi-dimensional understanding of the research topic. The data included in the data extraction table will be used to triangulate data obtained from the other activities within this study, adding to the validity and trustworthiness; ensuring that this research is scientifically sound. The data from the document review will further be used to identify factors that will influence the relevance and feasibility of an occupational therapy stroke program for the PHC setting.

3.4.3. ACTIVITY 2: STRUCTURED OBSERVATIONS AT PRIMARY HEALTH CARE CLINICS

Structured observations were conducted at the PHC clinics within the TMHD with the aim of assessing the physical environments at the PHC clinics and informing the

researcher of possible physical barriers and enablers that could influence the design of an occupational therapy stroke program.

As mentioned, the clinics were visited to establish the feasibility of rendering occupational therapy services at the clinics. The researcher aimed to detect whether the physical environments of the clinics were accessible to stroke survivors; whether there was space available to render therapeutic services as well as whether sufficient equipment was available to render occupational therapy services to stroke survivors. All of the aforementioned factors are essential to ensure that a designed program will be relevant and feasible for the PHC environment. The structured observations at the PHC clinics aimed at addressing objective two for this study, namely:

- To describe the structural factors regarding the physical environment available to render occupational therapy services to stroke patients within the PHC setting.

The research process that was followed to do the structural observations at the PHC clinics will henceforth be discussed.

3.4.3.1. Unit of analysis

The units of analysis for activity two (cf. Figure 3.1) of the research process was the PHC clinics within the TMHD. The TMHD is divided into six sub-districts. Within each of the sub-districts, there are a number of PHC clinics. The sub-districts, with the number of clinics for each sub-district indicated in brackets, are as follows: Mantsopa (9), Setsoto (11), Dihlabeng (9), Nketoana (6), Phumelela (5) and Maluti-A-Pofung (33). The research was conducted at the PHC clinics in the various sub-districts and the researcher gained entry to the clinics via the permanently employed occupational therapists within each of the sub-districts. At the time of the research, there was at least one occupational therapist working at PHC clinics within each sub-district.

3.4.3.2. Selection Criteria and Sampling

The researcher made use of non-probability purposive sampling. A sampling grid was used to identify the PHC clinics that were included in the structural observations for this

study. The researcher visited one clinic within each of the sub-districts. Table 3.2 indicates the sampling grid that was used.

The researcher purposefully chose the clinics. The researcher requested the

Table 3.2: Sampling Grid for Structured Observation at PHC Clinics within the Thabo Mofutsanyana Health District		
Sub-districts of the TMHD	Number of PHC Clinics within sub-district	Number of clinics actually visited and included in the study
Mantsopa	9	1
Setsoto	11	1
Dihlabeng	9	1
Nketoana	6	1
Phumelela	5	1
Maluti-A-Pofung ¹	33	2
Total number of PHC Clinics	73	7

permanently employed occupational therapists within each sub-district to identify the clinics that were been visited on outreaches. Not all clinics are visited on outreach and each sub-district determines which clinics are visited, based on their resources available. The researcher then chose one of the clinics that were visited per sub-district that was in close proximity to where other activities of this study were executed. The activities that were executed within the different sub-districts included the semi-structured interviews with the stroke survivors and the structured interviews with the CHWs. The clinics were also in close proximity of the researcher as the researcher already visited each sub-district for the other activities of the current study. A total

¹ Two clinics were included in the Maluti-a-Pofung sub-district as the pilot study was also included into the final data set.

number of seven clinics were finally included in the study as the clinic that was visited during the pilot study was also included in the sample.

By choosing these clinics, the researcher was able to triangulate data between activities three and four of the study.

The advantages of this sampling method included that the clinics were easily accessible and the execution of this activity was done simultaneously with other activities, limiting costs for the execution of the study. Other advantages also included the possibility of the triangulation of data, contributing to a realistic picture of shared experiences between the stroke survivors, the occupational therapists and the CHWs, as the context of PHC for these participants were similar. The disadvantages are however that the information gathered is limited as it only represents a very small portion of the total number of PHC clinics within the TMHD. The information thus cannot necessarily be generalized to all of the clinics within the district. Nonetheless, valuable information could be obtained regarding the structural factors that need consideration when designing an occupational therapy stroke program for the PHC setting.

3.4.3.3. Data collection tool

Botma *et al.* (2010, p.142) indicate that observations must be structured when it is used as a data gathering method and thus data must be quantified. The researcher compiled an observation checklist (Annexure D) for the purpose of the structured observations. Botma *et al.* (2010, p.143) state that a checklist can be used to record the evaluation of the phenomena under study - for this study - the PHC clinics. The researcher conducted an in-depth literature review to determine if there was any ready-to-use checklist. However, none of the checklists found was comprehensive enough to fulfil the purpose of this activity of the research phase. The researcher then compiled the observation checklist by making use of the document, *Accessibility of Health Care Facilities for Persons with Disabilities*, as provided by the NDoH (Department of Health n.d.). The information contained in the checklist was further supplemented with the document on occupational therapy departmental design as described by the FSDoH (Free State Department of Health 2007, pp.68–87). By making use of these documents, the

researcher ensured that the checklist was comprehensive, adding to the validity of the results of this study.

3.4.3.4. Pilot Study

Before the researcher commenced with the data collection for this activity, a pilot study was launched. Botma *et al.* (2010, p.275) define a pilot study as a "... small-scale version of the study". During the pilot study a PHC clinic, in close proximity to the researcher, was visited. The researcher was attentive to any errors in the composition of the checklist, unclear wording as well as errors on the section where information had to be captured. The researcher was also sensitive to observe whether any physical aspects of the clinics had been left out from the checklist.

The researcher completed the observation checklist manually. The researcher found the checklist to be user-friendly, easy to administer and the content was found to be comprehensive. After the pilot study, the data from the checklist was coded and the information was captured and entered into an Excel spreadsheet. The spreadsheet was sent to the Department of Biostatistics, Faculty of Health Science at the University of the Free State (UFS) where a biostatistician confirmed that the data were captured correctly and could be used for analysis.

As no changes were made to the data collection tool (observation checklist) and no errors in data collection procedures were found, the data from the pilot study was included into the final data for the study.

3.4.3.5. Research procedure and data collection

The data for this activity was collected by the researcher at the various PHC clinics identified. Prior to the collection of the data, the researcher did careful planning to ensure that the collection of data ran smoothly. The planning for the collection of the data included telephonic contact of the various clinic managers of the identified PHC clinics. The purpose of the study and the structural observations were explained and permission was obtained from the clinic managers to execute the research in their facilities. A date and time for data collection were communicated. Prior to the date of

data collection, the researcher sent a sealed envelope to each identified clinic via the occupational therapist who visits the clinic for outreach. The envelope included a copy of the approval granted by both the HSREC of the UFS (cf. Annexure A) as well as the Research Ethics Committee from the FSDoH (cf. Annexure B). The information document (Annexure E) regarding the structural observations was also included in the envelope. During the telephonic conversation, the researcher confirmed whether the clinic manager did receive the envelope. If the envelope was not received, the researcher sent the relevant information via email to the clinic managers.

On the day of the data collection (for each of the clinics) the researcher met up with the clinic manager and permission to execute the research was verbally obtained from the clinic manager after it had once again been confirmed that the letter requesting permission to perform the research at the clinic together with the approval letter from the FSDoH was received. The researcher then requested to be introduced to the clinic environment. Where rooms were locked, the manager was requested to unlock and allow the researcher to observe those rooms. For each aspect on the checklist, the researcher observed the environment and, where appropriate, measured the facility. The researcher indicated on the checklist if the different items were present and where applicable, a comment was recorded. An aspect was only regarded as sufficient if it met the criteria stated on the checklist - thus a mark of one or zero was awarded. The checklist took approximately 15 minutes to complete. The researcher took care in ensuring that the checklist was completed comprehensively before leaving the PHC clinic to avoid incomplete data.

3.4.3.6. Data Management

After the data was collected, the completed checklists were coded and the information was entered into an Excel spreadsheet. The data was entered into Excel twice and data were compared electronically to eliminate any data capturing errors. Where inconsistencies were found, the data was corrected manually. The completed checklist was safely stored in a locked cupboard to which only the researcher had access. The

checklists were scanned and stored electronically as well to prevent any loss of data. The data was saved on a password-protected computer.

3.4.3.7. Data Analysis

After all of the data was entered into Excel and all data was verified for accuracy, it was analysed by means of descriptive analysis with the assistance of the Department of Biostatistics, Faculty of Health Sciences at the UFS. The researcher and the biostatistician communicated where data sets were unclear and the possible errors were all investigated and corrected where applicable.

3.4.4. ACTIVITY 3: STRUCTURED INTERVIEWS WITH COMMUNITY HEALTH WORKERS

As part of phase one of this research study, structured interviews were also conducted with CHWs who are employed within the TMHD. The CHWs were included as they are one of the stakeholders when healthcare services are rendered to stroke survivors within the PHC context. The CHWs have direct access to stroke survivors, as they are visiting them in their homes.

Structured interviews were conducted. Botma *et al.* (2010, p.140) explain that structured interviews form part of quantitative research by using a set structured interview schedule. Structured interviews were chosen to form part of this research study due to its advantages in avoiding selection bias by preventing the exclusion of participants based on their level of literacy. This is due to the varied levels of literacy amongst CHWs in the TMHD. The structured interviews aimed at addressing objective two, three, four and five for this study, namely to describe:

- The structural factors regarding the physical environment available to render OT services to stroke patients within the PHC setting.
- The procedural factors regarding the understanding of the multi-disciplinary team on the roles of the OT when rendering services to stroke patients within the PHC setting.

- The procedural factors that are essential in ensuring OT intervention for stroke patients are relevant and feasible.
- The challenges stroke patients experienced while receiving OT services within a PHC setting.

The research process for the structured interviews with CHWs will henceforth be discussed.

3.4.4.1. Study Population

Botma *et al.* (2010, p.124) describe the study population as the entire set of persons who meet the sampling criteria. The study population for the structured interviews included the CHWs who are employed and working in the TMHD within the PHC setting. Each sub-district within the TMHD has a number of CHWs who are managed by a CHW coordinator. The CHW coordinator for each sub-district was contacted to identify the CHWs within the sub-districts. The coordinators identified the CHWs that met the inclusion criteria as well as those who were in close proximity to where the researcher conducted the other activities for this study. A total number of 52 CHWs were identified to participate in the study.

3.4.4.2. Selection Criteria

The CHWs who participated in the study were identified through an inclusion and exclusion criteria. The inclusion and exclusion criteria were set to ensure that the participants in the study had sufficient experience working with stroke survivors within the TMHD. The inclusion and exclusion criteria for this activity of data collection will henceforth be stated.

a) Inclusion Criteria

- CHWs employed within the TMHD responsible for providing health services to stroke survivors.
- CHWs who have worked within the TMDH for at least six months.

b) Exclusion Criteria

- CHWs who participated in the pilot study. These participants were excluded as the data collection tool, the structured interview schedule (cf. Annexure F), was altered and some changes were made to the content after the pilot study.

3.4.4.3. Sampling

A purposive sampling method was used in this activity, and specific health care providers were identified according to the stated inclusion and exclusion criteria. For the purpose of this activity of the research process, non-probability purposive sampling was used and CHWs were chosen purposefully according to the inclusion and exclusion criteria mentioned above. Only 32 CHWs participated in the study. The reason for this is due to the inclusion and exclusion criteria (cf. 3.4.4.2) as some of the identified CHWs did not meet the inclusion criteria. At some of the sub-districts there were a no-show of participants and some participants refused to participate. Sixty-one percent (n=32) of the available population were included in the study due to the small population size.

3.4.4.4. Data collection tool

A structured interview schedule (cf. Annexure F) was compiled and developed by the researcher by making use of relevant literature and the previous experiences of the researcher. The structured interview schedule included both closed-ended and open-ended questions. For some questions, specific response options were provided. The researcher took care in ensuring that questions were written in a simple and easily understandable language as the level of literacy was not known for all of the participants.

3.4.4.5. Pilot Study

Before the interviews were conducted with the CHWs, a pilot study was done. The pilot study consisted of two phases. During the first phase of the pilot study, the self-developed structured interview schedule was sent out to two occupational therapists working within the TMHD. The occupational therapists were asked to evaluate the

content of the structured interview schedule as well as to evaluate the language used. Only one therapist responded and changes were made to some of the wording of the questions to ensure a good level of understanding by the participants.

After the changes were made to the structured interview schedule, the researcher presented the structured interview schedule to three CHWs. The structured interview schedule was presented to the participants with the assistance of an interpreter. The interpreter is a physiotherapist who is working within PHC in the TMHD and is thus familiar with the phenomenon under study. The interpreter is also fluent in Afrikaans, English and Sesotho, thus limiting misinterpretations during translations. During the pilot study, the structured interview was presented to each one of the participants. Questions were presented in English by the researcher and where requested, they were presented in Sesotho by the interpreter. The researcher recorded the responses of the participants manually on the structured interview schedule. During the pilot study, it came to the attention of the researcher that some of the questions were unclear and changes were made to the wording as well as to some of the response options available.

After the structured interviews were completed and answers recorded, the researcher entered the data into an Excel spreadsheet. The data was entered into two separate Excel spreadsheets and thereafter the data was compared to determine if there were any data capturing errors present. Where errors were found, they were corrected to prevent measurement errors.

Since changes were made to the data collection tool during the pilot study, the information gathered was not included in the final data set and the participants in the pilot were excluded from the final data collected.

3.4.4.6. Research procedure and data collection

As mentioned previously, structured interviews, by means of an interview schedule, were held with CHWs who complied with the inclusion criteria. After the pilot study was completed and the structured interview schedules were finalised, the structured interview schedule was translated into Sesotho by a professional company.

Prior to the execution of the research, the researcher contacted the different CHW coordinators in the various sub-districts of the TMHD. The coordinators were informed of the purpose of this study and their permission was obtained to conduct interviews with the CHWs in their respective districts. The information document (cf. Annexure G) together with a copy of the approval granted by both the HSREC of the UFS (cf. Annexure A) as well as the Research Ethics Committee of the FSDoH (cf. Annexure B) were emailed to the coordinators. The information document (cf. Annexure G) was made available in Afrikaans, English and Sesotho. The date and time of the research execution was communicated with the coordinators and it was agreed that the interviews will take place at the local PHC clinics. The clinic managers of the respective clinics, where the research was performed, were also contacted to request their permission to conduct the interviews with CHWs within their facilities.

On the day of the interviews, the purpose of the study was explained to the participants who met the inclusion criteria and information documents (cf. Annexure G) were handed out in each participant's preferred language (documents were available in Afrikaans, English and Sesotho). Participants were made aware that participation in the study was voluntary and that they could withdraw from the study at any stage. The participants who chose to participate in the study were requested to sign a consent form that was also available in Afrikaans, English and Sesotho. Each participant was given a copy of the consent form (cf. Annexure H).

Thereafter the interview process commenced. The interviews were held individually in a private room. Only the researcher, interpreter and one participant were present in the room at a time. The questions on the structured interview schedule were presented to the participants in the same manner and no deviations were made (Botma et al. 2015a, p.140). The researcher conducted the interviews in English and recorded the responses of the participants manually on the structured interview schedules.

Where the participants requested, an interpreter presented the questions and translated the responses to the researcher. The same interpreter that assisted the researcher during the pilot study assisted the researcher during the data collection. The interpreter

made use of the exact same structured interview that was translated to Sesotho and care was taken in ensuring that no deviation was made from the structured interview schedule. The use of an interpreter was valued by the researcher as the majority of the participants' home language was Sesotho and not all of the participants felt comfortable with participating in the interview in English. The value and the trustworthiness of the data collected were not compromised as the participants were allowed to participate in the interview in their home language (Sesotho). After the participants responded, the interpreter translated the answers and the responses were manually recorded by the researcher on the structured interview schedules. The researcher ensured that the exact information was carried over by ensuring that the interpreter was properly informed on the expectations and the procedure that should be followed. The interpreter also agreed to keep all research information confidential.

3.4.4.7. Data Management

After the interviews were completed, the data for each sub-district was manually entered into Excel by the researcher. Data were entered twice and the two Excel spreadsheets were compared electronically to identify any errors in data capturing. Where transfer errors were found in the capturing of the data, it was corrected manually. This ensured that data transfer errors were eliminated, therefore strengthening reliability.

3.4.4.8. Data Analysis

The data was analysed, by means of descriptive analysis, with the assistance of the Department of Biostatistics, Faculty of Health Sciences at the UFS. The answers to open ended questions were analysed by means of quantitative content analysis. Statements were categorized and given numerical values, which were also analysed by means of a descriptive analysis, namely frequencies and percentages for categorical data.

3.4.5. ACTIVITY 4: FOCUS GROUP

Activity four forms part of the expert interviews as mentioned earlier (cf. 3.3.1. a). As this study focused on the profession of occupational therapy, the researcher decided to have a focus group discussion with the occupational therapists who are permanently employed within the TMHD. These occupational therapists can be seen as experts on the field of providing occupational therapy services to stroke survivors, specifically within PHC.

Greeff (2015, p.360) indicated that a group interview is conducted during a focus group with the aim of understanding how people think or feel about a service. Greeff (2015, pp.360, 361) added that a facilitator is used to guide the interview and the discussion in a non-threatening environment. Botma *et al.* (2010, p.210) added that the structure of the focus group is dependent on the style of the facilitator.

The use of a focus group was of particular value to this study as it allowed the researcher to gain an understanding of the perceptions of the important role players within the area of interest (Greeff 2015, p.361). Botma *et al.* (2015, p.210) emphasize that group interviews allow for obtaining multiple viewpoints on a specific topic. By making use of the focus group in the context of this study, the researcher was able to gain an in-depth perspective from various participants who each have their own repertoire of experience, challenges and suggestions for providing occupational therapy services to stroke survivors in the TMHD. Other advantages of using a focus group for the specific objectives of the study, included that the responses shared in the group could have triggered ideas in the minds of other participants and these ideas could be developed within the focus group (Plummer-D'Amato 2008a, p.70).

The focus group aimed at contributing towards all of the objectives for this study, namely to describe:

- The structural factors regarding the relevance of the current regulatory documents (including policies, procedures, referral guidelines and human resource plans) within the TMHD on the provisioning of OT services to stroke patients within the PHC setting.

- The structural factors regarding the physical environment available to render OT services to stroke patients within the PHC setting.
- The procedural factors regarding the understanding of the multi-disciplinary team on the roles of the occupational therapist when rendering services to stroke patients within the PHC setting.
- The procedural factors that are essential in ensuring OT intervention for stroke patients are relevant and feasible.
- The challenges stroke patients experienced while receiving OT services within a PHC setting.

The use of focus groups for the current study will henceforth be discussed.

3.4.5.1. Research population

As this study focused on the profession of occupational therapy the research population comprised of permanently employed occupational therapists working with stroke survivors within PHC in the TMHD. At the time of the execution of the study, there were seven permanently employed occupational therapists (including the researcher) at District Hospitals within the TMHD. The minimum years of experience was 4 years and the maximum years of experience was 22 years amongst the occupational therapists. None of the occupational therapists had any postgraduate qualifications.

3.4.5.2. Selection Criteria and sampling

For the purpose of the focus group, non-probability, purposive sampling was used and all of the permanently employed occupational therapists working within the TMHD were invited to participate in the study. Participation in the focus group was voluntary and participants were informed that they may withdraw at any stage during the study.

The researcher made use of eligibility criteria in the form of inclusion and exclusion criteria, to identify the participants that were invited to participate in the focus group.

a) Inclusion Criteria

- Occupational therapists permanently employed at a District Hospital within the TMHD.

b) Exclusion Criteria

- Occupational therapists working at Regional Hospitals within the TMHD.
- Community service occupational therapists working at either a District or Regional hospital.
- The researcher.

The researcher chose to not be part of the focus group discussion to prevent prejudice and bias in the data collected. The researcher further also chose to exclude therapists from Regional Hospitals as they do not form part of the PHC structure and context. Community service occupational therapists were also excluded as they may not have had sufficient experience within PHC and/or with stroke survivors to contribute meaningfully to the study.

A total number of four participants participated in the focus group.

3.4.5.3. Research procedure and data collection

For the purpose of the focus group, the researcher chose to make use of an external group facilitator to guide the interview. Reasons for using an external facilitator were, firstly, to prevent bias in the collection of the data, secondly, the researcher does not have experience in facilitating focus groups, thus an experienced facilitator was preferable, and lastly, it allowed the researcher to observe and make field notes on the participants' interactions and body language during the group discussion.

The researcher did careful planning to ensure that the focus group would be attended by the participants, ensuring a high response rate. The researcher chose to conduct the focus group in Bethlehem as it is the most central point for all therapists within the TMHD. The researcher further scheduled the focus group after a district rehabilitation

meeting since all of the permanently employed therapists are required to attend monthly meetings. This resulted in a high response rate and also limited costs for the researcher as transportation for the therapists was already provided by the FSDoH for the occupational therapists to attend the meeting.

A month before the focus group, the researcher informed the permanently employed therapists regarding the focus group and invited all of them to participate. The information sheet as well as details on the arrangements for the focus group was handed to them in an envelope. The information sheet (cf. Annexure I) was made available in English only as it is the official language of communication within the FSDoH, and all health care professionals are required to be fluent in English in order to perform their duties (Department of Health 2015, p.6). A week before the focus group the researcher reminded the participants about the invitation to participate in the study and it was mentioned to them that participation is voluntary and that they may withdraw at any stage without any negative consequences.

On the day of the interview, four of the six occupational therapists who were eligible to participate (cf. 3.4.5.2.) agreed to attend and participate in the focus group. The focus group was held in a private room at the District hospital in Bethlehem. All of the participants were greeted and the researcher made them feel at ease by providing some snacks and beverages since the group was held around lunch time. Once the participants felt at ease, everybody, including the researcher and the group facilitator, took their seats in a circular formation.

The researcher explained the purpose of the research as well as the process that will be followed during the focus group. The group facilitator was also introduced to the participants and her role in the focus group was also explained. The researcher explained the use of audio recorders and emphasized that all information will be kept confidential. Voluntary consent was again emphasized and participants were reminded that they may withdraw from the study at any stage. Verbal contracting for the confidentiality of the group content was also done prior to commencement of the focus group. After all uncertainties were cleared, the researcher handed out consent forms (cf.

Annexure J) to the participants. The consent forms were signed by the therapists as well as a witness.

As mentioned, a skilled facilitator facilitated the focus group and the researcher was responsible for taking field notes during the group discussion. The facilitator presented an in-depth question to the participants:

How do you see your role as an occupational therapist in the management of your stroke clients?

The group facilitator started the discussion with the question above, and the interview schedule (cf. Annexure K) was used to guide the discussion towards further topics relating to the main question. Therapists were given the opportunity to reflect on their role in rendering services to stroke survivors both within the PHC setting as well as within the district hospital setting. This was done to gain a holistic understanding of the position of the occupational therapists within the TMHD. During the focus group discussion, a number of secondary themes also emerged that gave valuable information towards understanding the functioning and challenges of the occupational therapy intervention to stroke survivors within the TMHD. The discussion was audio recorded on two recording devices. Two devices were used to prevent loss of data as well as ensuring that the best quality recording could be used for transcription.

3.4.5.4. Data Management

After the focus group was held, the audio recording was transferred onto a password-protected computer and the recording on the voice recorder was deleted. The group discussion was transcribed with the assistance of an external professional transcription company. The audio file was uploaded on the website of the company and confidentiality was guaranteed by the company. The company provided the researcher with the transcription of the content of the focus group interview. The researcher verified the content of the transcription by listening to the audio file while reading through the transcription. Where errors occurred, the researcher corrected it manually on the transcription.

3.4.5.5. Data Analysis

The researcher analysed the focus group data with the assistance of a co-coder. The researcher and the co-coder individually analysed the data before the analysed data was compared and a final conclusion was made. For the purpose of the analysis, Creswell's (2009) method of data analysis for qualitative research was used, as cited in Botma *et al.* (2015, pp.223–225). The data analysis was deductive in nature. The data analysis process is divided into six steps by Cresswell (2009). The steps will be described as it was applied for this current study:

Step one: Organise and prepare data. The focus group data was transcribed and checked for any errors as discussed under data management (cf. 3.4.5.4.).

Step two: Develop a general sense. The focus group transcription was read through to gain an overall understanding of the group. General notes on emerging codes and categories were made in the margins of the transcription.

Step three: Coding the data. After a general sense of the data was obtained, both the researcher and the co-coder individually coded the data. According to Botma *et al.*, (2015, p.244) "Coding is the process of organising the material into chunks or segments of text before bridging meaning to the information" while Saldaña (2009, p.3) describes a code as "... a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data."

The specific coding method used was descriptive coding. Descriptive coding is defined as using a word or short phrase to summarize the basic topic that is brought forward by a passage of qualitative data (Saldaña 2009, p.70). The codes were developed from the information that emerged from the participants and an open-ended approach was followed. The codes were then grouped together to form categories. Coding allowed the researcher to group similarly coded data, that shared some characteristics, together into categories (Saldaña 2009, p.8).

After the individual coding and categories were done, the researcher and the co-coder presented their findings to one another and codes and categories were compared. Data was mostly similar and no codes were added. The researcher and the co-coder then discussed the categorization of the data.

Step four: Describe and identify themes. After the codes and categories were agreed upon by the researcher and the co-coder, emerging themes were discussed and described. Saldaña (2009, p.13) states that a theme "... is an outcome of coding and categorization."

Step five and six: Representing findings and interpreting data. These steps will be discussed in detail in Chapters 4 and 5.

3.4.6. ACTIVITY 5: SEMI-STRUCTURED INTERVIEWS

Activity five of this research study is the last set of data that formed part of the expert interviews (cf. 3.3.1. a). Since the stroke population were under study, their contribution to the study was invaluable. The stroke survivor is the expert on identifying the challenges and the barriers that are faced with when seeking occupational therapy services within PHC. With this set of data, the researcher aimed at gaining an in-depth understanding of the perceptions of the stroke survivor.

The researcher chose to make use of semi-structured interviews. Greeff (2015, p.351) and Botma et al. (2015, p.208) indicate that semi-structured interviews are used when the researcher wants to understand how the participant perceives a specific topic.

The semi-structured interviews aimed at addressing objectives two, four and five for this research study, namely to describe:

- The structural factors regarding the physical environment available to render OT services to stroke patients within the PHC setting.
- The procedural factors that are essential in ensuring OT intervention for stroke patients are relevant and feasible.

- The challenges stroke patients experienced while receiving OT services within a PHC setting.

The application of the semi-structured interviews for the current research study will henceforth be discussed.

3.4.6.1. Research population

The population under study was the stroke survivors who were attending and receiving occupational therapy services within PHC in the TMHD at the time of the execution of the research. There is an average of 50 stroke patients who are attending occupational therapy sessions per month between the six sub-districts in the TMHD (Free State Department of Health 2016b). These stroke survivors are attending therapy at either the district hospital or the PHC clinic. The stroke survivors range from very young to the elderly – no specific data was available on the ages of the stroke survivors at the time of the execution of this study.

3.4.6.2. Selection criteria and Sampling

For the purpose of this activity of the research, non-probability, purposive sampling method was used and stroke survivors were chosen purposefully according to inclusion and exclusion criteria. These stroke patients were also chosen according to accessibility and availability.

The stroke survivors were chosen per sub-district to allow an even presentation of all stroke survivors within the TMHD. This was further done to ensure that not only stroke survivors treated by a single therapist is chosen. Permission was obtained from the FSDoH to allow the permanently employed occupational therapists from the various sub-districts within the TMHD, to identify suitable stroke survivors for possible participation in the research and according to the inclusion and exclusion criteria. Each therapist was requested to identify at least two participants (one male and one female) who met the set criteria. The researcher intended on only interviewing six participants, however, a total of 12 participants were nominated in order to have a sufficient number

of participants in the event that participants did not show up for the interview or if data saturation was not met after interviewing six participants.

The inclusion and exclusion criteria were as follow:

a) Inclusion Criteria

- Stroke survivors who have received occupational therapy treatment for a minimum of six months at a District Hospital within the TMHD or stroke survivors who have received occupational therapy treatment for a minimum of six months at a PHC clinic within the TMHD.
- Stroke survivors who have completed their rehabilitation process and who have been discharged from therapy (chronic stroke survivor).
- Stroke survivors who were able to communicate verbally to ensure the accurate gathering of information.
- Stroke survivors who were able to follow instructions and answer simple questions to ensure the accurate gathering of information.
- Stroke survivors that may have been wheelchair bound and may have had loss of function from one or more limb at the time of the study.

b) Exclusion Criteria

- Stroke survivors who have not completed at least six months of occupational therapy treatment on a district level (district hospital or PHC clinic).
- Stroke survivors who have received occupational therapy at a Regional hospital in the TMHD.
- Stroke survivors that present with global or expressive aphasia, as they would not be able to participate meaningfully in an interview.
- Stroke survivors presenting with impairments of their cognitive functioning.

The researcher acknowledges that the stroke survivors who were excluded from the study may have brought forward relevant information regarding the phenomena under study and that this is a limitation to the current study. However, for the purpose of this

study they were not included as the chosen methodology would not have been practicable. This study only focused on the general experiences of stroke survivors and in-depth research on the different types of impairments that influence stroke survivors can be done in future research.

3.4.6.3. Data collection tool

For the purpose of the semi-structured interviews, the researcher made use of a semi-structured interview schedule (cf. Annexure L). Greeff (2015, p.342) indicated that qualitative research are often collected by means of an interview and added that stories are told through the interview process that is essentially a meaning-making process. Semi-structured interviews are used to collect these stories and Botma et al. (2015, p.208) indicates that a semi-structured interview offers the researcher the flexibility to follow up any interesting discussions that emerge during the interview. Furthermore, Botma et al. (2015, p.209) adds that the interview schedule only serves to guide the discussion and that it should not necessarily dictate the interview. The interview schedule included pre-determined, open-ended questions that guided the interview with the patients, as advised by Botma *et al.* (2015, p.209). The interview schedule was developed by the researcher by making use of own experiences as well as information found in literature (Chapter 2) and activity one of the research (cf. 3.4.2.). The interview schedule took about 20-30 minutes to complete.

3.4.6.4. Exploratory Study

Before the researcher commenced with the interviews, an exploratory study was done. This was done to inform the researcher on the comprehensiveness of the interview schedule as well as to provide an opportunity for the researcher to gain confidence with the interview process and also to ensure that the data generation methods yielded usable data and were user-friendly.

During the exploratory study, two stroke survivors were purposefully chosen for participation. The stroke survivors were both Sesotho speaking and the researcher made use of an interpreter to translate the interview between the researcher and the

participants. The interpreter was the same physiotherapist who assisted the researcher during activity three. By making use of the same person as interpreter, trustworthiness and rigour was strengthened as the interpreter's skills were applied consistently throughout the study.

The exploratory research activity was conducted at the hospital where the researcher was employed at the time of the research. The researcher conducted semi-structured interviews with both of the participants by making use of the interview schedule to guide the discussion. During the interview, the researcher found that the use of an interpreter can be extremely difficult in a semi-structured interview situation, compared to a structured interview (cf. 3.4.4.). After the exploratory investigations, the researcher and the interpreter defined their separate roles to prevent inaccurate data for the data collection.

The exploratory research's data were not included in the data analysed for this activity of the research due to two main reasons: the two participants did not meet the inclusion criteria for the study and the roles of the interpreter and researcher (interviewer) were not clearly defined and may have influenced the validity of the data collected.

3.4.6.5. Research procedure and data collection

As mentioned, the researcher requested the permanently employed therapists at the district hospitals to identify stroke survivors who met the inclusion criteria for this activity. After the researcher chose the participants purposefully, the occupational therapists were requested to communicate the information regarding the voluntary participation in the study to the stroke survivors. The occupational therapists were well informed regarding the research process as well as the inclusion and exclusion criteria. The therapists were all gathered for a meeting when the information was shared. During the meeting, each therapist was supplied with an information documents (cf. Annexure M) that was available in Afrikaans, English and Sesotho. They were requested to hand it to the stroke survivors and explain the process to them. If the stroke survivors agreed to participate, the therapists were requested to arrange the time, date and suitable venue with the stroke survivors to meet the researcher and the interpreter.

A week before the interview, the researcher contacted all of the therapists telephonically to confirm if the stroke survivors agreed to participate as well as to confirm the logistical arrangements for the day of the interview. After the therapists confirmed the venue for the interview, the therapist obtained verbal permission from the manager at the PHC clinic/Occupational Therapy Department to have the interview in his/her institution. The venues were all therapy rooms with a closing door where the stroke survivor, researcher and interpreter conducted the semi-structured interviews in private.

On the day of the interview, the researcher made sure that the venue selected by the therapist was private in order to ensure confidentiality and to ensure that stroke survivors would feel at ease during their participation. As soon as the stroke survivors arrived, they were greeted and the information document (cf. Annexure M) was presented to them in their language of preference. Although the information documents were already handed out to them previously by their therapist, it was done again to ensure that the stroke survivors are aware of the purpose of the research as well as to ensure that they were not forced to participate. The information documents were also handed out again to ensure that the stroke survivors are fully informed on the procedure of the data collection. The use of the audio recorders was also explained and thereafter the stroke survivors were offered the opportunity to give voluntary consent to participate in the research study. They were also informed that they may withdraw from the study at any time without any negative consequences. Each participant voluntarily signed an informed consent form (cf. Annexure N). The stroke survivors were reimbursed for the transportation costs they have encountered to travel from their homes to their closest health care facility (District Hospital or PHC clinic) to participate in the study. The local transportation fare was confirmed with the therapist beforehand and patients were reimbursed accordingly. Patients also signed a reimbursement form (cf. Annexure O) stipulating the amount as well as an explanation of why they were reimbursed.

Thereafter the researcher commenced with the semi-structured interview by making use of the interview schedule. The interpreter was responsible for translating all information between the researcher and the participants. By allowing patients to participate in the interview in their home language (Sesotho), the value and trustworthiness of information

carried over were not compromised. The researcher ensured that the interpreter carried over the information correctly by carefully informing the interpreter on the expectations and process of exchanging the data. It is important to note that the discussions did not necessarily follow the exact content of the interview-schedule as the discussions led the interview. Two voice recorders were used during the interview to prevent the loss of data due to a faulty recorder. After the completion of the interview, the stroke survivors were offered some refreshments.

Data collection was continued until data saturation was met. A total of seven stroke survivors were interviewed as one of the participants who was interviewed did not meet the inclusion criteria and could thus not be included in the data. This participant has only received one month of occupational therapy at her PHC clinic. This was a human error that was made by the occupational therapist serving that PHC clinic and unfortunately the participant was excluded. In total, six interviews were conducted. The six interviews were conducted at four District Hospitals and two PHC clinics. The duration of the interviews were between 14 and 40 minutes long.

3.4.6.6. Data Management

After the interviews, the researcher transferred the audio recordings onto a password-protected computer. The recordings on both audio recording devices were deleted. Each interview was transcribed with the assistance of an external transcription company who specializes in the language of the participants (Sesotho). Each audio file was uploaded by using *WeTransfer*, an internet-based file transferring system that ensures confidentiality of files is maintained at all times. The company was responsible to translate all of the Sesotho transcriptions to English. This was done to ensure no information was carried over incorrectly as well as to ease the analysis of the data obtained. The company provided the researcher with a transcription for each interview. To ensure the accuracy of the data and translations, a physiotherapist, fluent in Sesotho and English, verified the contents of the transcriptions by listening to the audio clips and comparing the contents of the document. Errors identified by the physiotherapist were corrected manually by the researcher.

3.4.6.7. Data Analysis

Creswell's (2009) method of data analysis was used to analyse the data from the semi-structured interviews, as discussed under the focus group (cf. 3.4.5.6). The researcher and a co-coder (a different co-coder than the co-coder mentioned under section 3.4.5.5) both analysed the data individually by assigning codes to the data. After the codes have been assigned, the findings were presented and discussed. Descriptive, open-ended coding was used. After the codes were discussed, the researcher and the co-coder developed categories and thereafter themes were developed. The data analysis was deductive in nature.

3.4.7. ACTIVITY 6: SURVEY QUESTIONNAIRE WITH MEMBERS OF THE MULTI-DISCIPLINARY TEAM

A structured survey was planned as part of phase one for this research study. The survey questionnaire was to be sent to allied health professionals as well as medical officers and registered nurses who are working within the PHC setting. Unfortunately, this activity was not executed due to a number of challenges out of the researcher's control. These challenges included no internet access at the PHC clinics to conduct an electronic questionnaire as well as the FSDoH not being able to supply the researcher with contact details for the chosen population group. Although this activity was not executed, the other data sets still answered all of the objectives for this study.

3.5. VALIDITY AND RELIABILITY OF DATA

This section on validity and reliability will focus on the quantitative data elements that were included in the study, namely the structured clinic observations and the structured interviews with the CHWs. Delport and Roestenburg (2011, p.173) indicated that validity consists of two aspects, namely: that the concept of the question must be measured by the instrument and that the measurement of the concept must be accurate. The validity aspects of the data collection tools will henceforth be discussed.

The researcher ensured the validity of the data collected through the structural observations and structured interview schedule through a number of actions. Firstly, the

researcher ensured that a thorough literature review was done before the contents of the structured interview schedule, checklist and interview schedule were compiled. By doing a thorough literature review, vague concepts were prevented and content validity was strengthened (Botma et al. 2015a, p.175). Secondly, the researcher aimed to use optimal sample sizes to ensure the rigour of the survey structured interview schedules as well as the structured interviews by making use of a probability sampling method (Botma et al. 2015a, p.175). Thirdly, the validity of the information gathered was promoted by pre-testing the data generation tools to ensure its effectiveness and to prevent measurement errors (Botma et al. 2015a, p.175). Fourthly, the researcher chose appropriate assessment tools for each population and setting where data was gathered as advised by Botma *et al.* (2015, p.176). Lastly, the researcher conducted a peer review of the data collection tools by requesting two occupational therapists, skilled and experienced in the field of stroke rehabilitation, to review the tools. During the review, the occupational therapists were requested to evaluate the content as well as the user-friendliness of the tools. The peer review was done to ensure that the information received from the measure would be reliable, that questions were clear and unambiguous and to obtain an indication beforehand of the time it would take to complete the structured interview schedule. The peer review was further done to eliminate typing and spacing errors that can make the utilization of the measures difficult, resulting in poor outcomes.

The validity and reliability of data did not end with the preparation of the collection of the data. During data collection, care was taken by the researcher to record and document all responses from the CHWs accurately and precisely. The same procedure was followed during the observations at the PHC clinics. The researcher took care to prevent interviewer bias during the structured interviews and strived toward being unambiguous and objective throughout all data gathering procedures. The structured interview schedule was also made available in English and Sesotho, ensuring that no information was lost or misinterpreted due to a language barrier as well as allowing all participants to fully express themselves in a language that they felt most comfortable in.

With data capturing, the researcher limited measurement errors by checking the coding of the checklists and the interview schedule by entering the data into Excel twice and comparing the data that was entered electronically. Errors that occurred were identified, investigated and corrected. The researcher also ensured that accurate data analysis techniques were applied (Botma et al. 2015a, p.176).

3.6. QUALITY AND RIGOUR OF DATA: TRUSTWORTHINESS

This section will focus on the qualitative data elements that were collected during this study that included the document analysis, focus group and the semi-structured interviews. For the semi-structured interviews as well as the focus group, relevant aspects of trustworthiness will henceforth be discussed. Lincoln and Guba (1985, in Plummer-D'Amato 2008b, p.123) describes the criteria for trustworthiness according to four aspects, namely: creditability, transferability, dependability and confirmability. Each aspect will be discussed individually with its specific reference to this study.

3.6.1. Credibility

Lincoln and Guba (1985, in Plummer-D'Amato 2008b, p.123) describes credibility as the internal validity of the study. Schurink, Fouche and De Vos (2011, p.419) indicate that the goal of credibility pertains to "... demonstrate that the inquiry was conducted in such a manner as to ensure that the subject has been accurately identified and described." The researcher was responsible for conducting the semi-structured interviews and the researcher was also present as fieldworker during the focus group. Although the researcher only visited each district once, she is familiar with the context and setting of stroke survivors as the researcher, at the time of the study, was employed within the PHC setting and worked with stroke survivors on a daily basis. The knowledge of the context and the setting of the stroke survivors, together with the researcher's active involvement in the analysis of the data, added to the credibility of the data collected. It further assisted the researcher in exploring the problem at hand and describing the setting of the stroke survivors effectively as advised by Schurink, Fouche and De Vos (2011, p.420).

Triangulation of the data collected was done with other data sources and research methods (Botma *et al.* 2015, p.234; Schurink, Fouche and De Vos (2011, p.420). Triangulation refers to the use of "... more than one measure to measure the construct ..." thus indicating that the construct validity of the data obtained is high when it is supported by other data sets which measured the same construct (Botma *et al.* 2015a, p.176). The qualitative data was triangulated with both the quantitative data as well as the literature review to ensure that the data collected was credible and trustworthy.

As the researcher is still inexperienced with the execution of qualitative research, a lot of guidance was sought from both the study leader and the co-study leader for this study. The process of qualitative data gathering for this study was also approved prior to the execution of the study by a number of committees that included an expert committee, two evaluation committees as well as the HSREC. After approval was granted from the HSREC (cf. Annexure A), approval was also obtained from the Free State Department of Health Research Committee (cf. Annexure B). The researcher gained a lot of insight into the process of interviewing during the exploratory investigations for the semi-structured interviews. Lessons learnt from the exploratory investigations were applied during the main data gathering to add to the credibility of the research. The researcher further invited an occupational therapist, who is skilled and experienced in conducting and analysing focus groups, to assist the researcher in the conduction of the focus group. Lastly, the researcher made use of co-coders to code the qualitative data, ensuring that the analysis of the data is trustworthy. As described (cf. 3.4.6.1.; 3.4.6.7.), coding was done independently by each coder, and then compared to establish whether the coders agreed on the analysis of the data.

3.6.2. Transferability

Lincoln and Guba (1985, in Plummer-D'Amato 2008b, p.123) describes transferability as the external validity of the study. The researcher has made use of multiple sources of data (Schurink, Fouche and De Vos 2011, p.420). The multiple data sources allowed for triangulation between different stakeholders. The triangulation ensures a more reliable outcome of the research study and it strengthens its usefulness for other settings

(Schurink, Fouche and De Vos 2011, p.420). Schurink, Fouche and De Vos (2011, p.420) added that transferability entails the ability of the research findings to be transferred from a specific situation to another and it can also be referred to as generalizability.

Transferability was, however, not the main important measure of quality in the current study. Van den Akker (n.d., p.12) states that findings cannot be generalised based on statistical techniques but rather on 'analytical' forms of generalization. This entails that readers should be "... supported to make own attempts to explore the potential transfer of the research findings" (Van den Akker n.d., p.12). In order to achieve this, the researcher has made use of contextual descriptions to provide thorough information on the various participants and their different contexts.

3.6.3. Dependability

Lincoln and Guba (1985, in Plummer-D'Amato 2008b, p.123) equates dependability to the reliability of the study. Schurink, Fouche and De Vos (2011, p.420) added that dependability also refers to "... whether the research process is logical, well documented and audited." The researcher has ensured dependability by delineating all qualitative methodologies and describing all the steps in the execution of the data collection, management and analysis in detail.

Lastly, the researcher made use of investigator triangulation (Botma et al. 2015a, p.235) by making use of co-coders (cf. 3.4.5.5. and 3.4.6.7.). Co-coders were used to ensure that the analysis of the data is trustworthy as well as to prevent any form of bias. Dependability was strengthened through the multiple methods that were used for this study. Triangulation between the various data sets and the different stakeholders contributed to the dependability of the study.

3.6.4. Confirmability

Lincoln and Guba (1985, in Plummer-D'Amato 2008b, p.123) and Schurink, Fouche and De Vos (2011, p.421) describes confirmability as the objectivity of the study. The researcher kept an audit trail of all data gathered as well as of field notes that were

made during the execution of the study and its activities. Confirmability was further enhanced by the use of triangulation between multiple data sets as well as the different stakeholders (cf. 3.6.2.) to strengthen the results and outcome of the study.

3.7. ERRORS IN DATA COLLECTION

Although special care was taken to prevent errors during data collection, it is still possible that errors could have occurred. The following list indicates possible errors:

- Botma *et al.* (2015, p.142) argue that it is difficult to fully eliminate bias with structural observations. This implies that the researcher may have been biased in the execution of the checklists of the structural observations of the PHC clinics. The researcher aimed at completing the checklist objectively and only according to the instructions on the checklist.
- Interviewer bias could have occurred by the researcher in subconsciously influencing the participants to answer the questions in a certain manner (Botma et al. 2015a, p.85). This may have occurred in the way the researcher presented questions or statements to the participants. The researcher, however, attempted to be as neutral as possible and attempted to ask non-biased questions and adhere to the manner in which the interview schedule was prepared and constituted.
- The researcher was not familiar with the stroke survivors and this may have had an influence on their trust in the researcher. Special care was taken to put the participants at ease and the confidentiality aspects were emphasized.
- The participants in the focus group were, however, known to the researcher and to the other group participants and this could have influenced their full participation and honesty. The researcher reiterated to all participants that the information would be kept confidential and their identities would be protected.

3.8. ETHICAL CONSIDERATIONS

Strydom (2011, p.114) defines ethics as follows:

Ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.

Ethical considerations have been applied in this study and the various ethical aspects (as described by Botma *et al.* (2015, pp.115–126)) will be discussed individually:

3.8.1. Approval of ethical committee

Before the researcher conducted any research, a research protocol was compiled. The protocol was reviewed by the Expert Committee of the Department of occupational therapy as well as the Evaluation Committee of the School for Allied Health Professions. Thereafter, the protocol was submitted for review and approval at the HSREC of the University of the Free State. After approval was granted by the HSREC (approval number UFS-HSD2017/0304), the protocol and confirmation of approval of the HSREC (cf. Annexure A) was submitted to the Research Ethics Committee of the FSDoH. Only once approval was also obtained from the Research Ethics Committee from the FSDoH (cf. Annexure B), the researcher commenced with the execution of the study.

3.8.2. Avoidance of harm

The study did not hold the risk of any physical harm to the participants. Care was taken to limit the emotional harm that participants could have experienced during participation. Emotional harm could have been evoked by questions that led to unpleasant emotions. If any unpleasant emotions were reported, debriefing services would have been offered to the participants as per the research protocol.

3.8.3. Voluntary participation

All participants were given the opportunity to voluntarily participate in the study after a thorough information document was explained to them. This ensured that participants could make an informed decision to voluntarily participate. All participants were also given the opportunity to withdraw from the study at any stage.

3.8.4. Informed consent

Before any of the research participants engaged in any of the data gathering methods, an informed consent form was presented to them. Participants were requested to sign the informed consent form (cf. Annexure H, J, N). Again, the informed consent was only signed after the information document (cf. Annexure G, I, M) was explained to participants in detail. The information document contained all relevant information regarding the background and purpose of the study, the invitation to participate in the study, what is involved in the study, possible risks and benefits as well as the ethical considerations and confidentiality. The consent form was completed in writing and it was signed by the researcher, the participant as well as a witness. No participants indicated that they are illiterate or was unable to sign to sign the consent form. Each participant was also handed a copy of the signed consent form. A paper trail of the consent forms was kept safe in a cabinet which was only accessible to the researcher.

3.8.5. Deception of respondents

The researcher took care to not mislead or deliberately misinterpret facts. The researcher also did not withhold any information from the participants.

3.8.6. Violation of privacy/anonymity/confidentiality

The researcher took care in safeguarding the privacy and anonymity of all participants. All names or identification that could link a document with a person, was removed. All documents were identified only by participation numbers. The researcher further ensured that all information that was gathered was kept confidential. Audio recordings were loaded onto a password-protected computer and all paper trails with confidential

information were locked away in a lockable cabinet to which only the researcher has access. All participants were also informed of the use of field notes as well as the use of audio recorders. The researcher undertook verbal agreements with the persons who assisted with the facilitation and interpretations of the semi-structured interviews as well as the focus group, to keep the information confidential and to respect the right of privacy of the participants. The interpreter/facilitator/coders were all occupational therapists and physiotherapists who are also bound by the HPCSA rules in term of patient ethics.

3.8.7. Actions and competence of researcher

The researcher took care in ensuring that she was well equipped and trained to conduct the research at hand. The researcher was under the supervision of two study leaders and where the researcher was in doubt, guidance and assistance were sought from the study leaders. A facilitator was used during the focus group to ensure that the data was gathered accurately, as the researcher did not feel adequately skilled. The researcher further ensured that all actions conducted were ethically sound. The researcher also took special care in preventing any form of plagiarism in the research proposal and report.

3.8.8. Publication of findings

All participants in the various activities of this study were informed that the findings of this study may be published and presented at relevant research forums. The final findings of this study will also be distributed within the TMHD via electronic communication methods such as email. The findings will also be communicated to the permanently employed occupational therapists for their own information and to share with the stroke survivors they identified to participate in the study. The same process will be followed with the CHWs - the findings will be communicated to the CHW coordinators in the TMHD.

3.8.9. Other ethical considerations

- No remuneration was given to any of the participants for participating in the study. Only the stroke survivors were reimbursed for the transportation costs they incurred to participate in the study.
- All data was deleted from the audio recording devices; contributing to keeping all information confidential. All names were also removed from all of the interview transcripts of the focus group interview as well as the interviews with stroke survivors.
- Participants could have participated in the language of their choice.

In conclusion, the researcher undertook to maintain a high standard of confidentiality during the research process and it was of utmost importance to keep all information confidential.

3.9. CONCLUSION

This chapter focussed on the methodological considerations for the current study. Since this study consisted of five data collection activities, each activity was described individually. The activities consisted of a document review, structured clinic observation, structured interviews, a focus group as well as semi-structured interviews. This chapter also reviewed the validity and reliability as well as the trustworthiness of the data collected. Lastly, this chapter considered the ethical considerations involved in this study. All of the mentioned data collection procedures assisted the researcher in identifying the factors that will influence the design of an occupational therapy stroke program within PHC.

Table 3.3 summarizes the data collection methods as well as the objectives (1-5) that are intended to be answered by the different sets of data. The table also indicates in which of the following chapters the presentation and interpretation of data can be found.

Table 3.3: Summary of data collection activities and the objectives met by each activity (compiled by the researcher)					
	Activity one	Activity two	Activity three	Activity four	Activity five
Data collection Tool	Document Analysis	Structural observation checklist	Structured interviews	Focus Group	Semi-structured interviews
Objectives addressed	1, 5	2	2, 3, 4, 5	1, 2, 3, 4, 5	2, 4, 5
Interpretation and discussion of data	Chapter 4	Chapter 4	Chapter 4	Chapter 4	Chapter 5

As can be seen from Table 3.3, the different activities will be discussed in two separate chapters. Activity one, two, three and four will be discussed in Chapter 4 where the focus will fall on the health system and the health care workers' perspective. Activity five will be discussed in Chapter 5 where the focus will fall on the client perspective. For both of these chapters, the data will be presented and discussed.

CHAPTER 4: PRESENTATION AND DISCUSSION OF RESULTS AND FINDINGS: HEALTH SYSTEM AND HEALTH WORKER PERSPECTIVE

4.1. INTRODUCTION

While the previous chapter focused on the various methodologies that were used for this study, the findings of the different data sets will henceforth be discussed. Chapters 4 and 5 relate directly to one another with the exception of one data set. In this chapter the following data sets will be presented, interpreted and discussed: the document review, the structural observation checklist, the structured interviews with the CHWs and the focus group with occupational therapists. The data from the semi-structured interviews with the stroke survivors will be discussed in Chapter 5. Both these chapters will aim at answering the research question for this study:

What are the factors that will influence the relevance and feasibility in the design of an occupational therapy program for stroke patients within a rural PHC setting in the THDH?

For each of the data sets the researcher will orientate the reader to the demographic information of the participants (where applicable) and thereafter the interpretation and discussion of the data will be presented within the context of relevant literature.

4.2. DOCUMENT REVIEW

The research process commenced with a document review with the objective to identify the structural factors regarding the relevance of the current regulatory documents (including policies, procedures and referral guidelines) to the provisioning of occupational therapy services to stroke survivors within the PHC setting in the TMHD. The document review further sought to identify the indispensable procedural factors to ensure relevant and feasible occupational therapy intervention for stroke survivors.

4.2.1. Demographic information

The document review included a total number of 11 public healthcare documents that relates specifically to PHC, occupational therapy and stroke. The public healthcare documents were selected purposefully for their specific relevance to the rendering of occupational therapy services within the Free State and especially in the TMHD. Where no provincial documents could be obtained, national public health care documents were used. The documents included in the document review are listed below:

1. Free State Department of Health Strategic Plan 2015/16-2019/20 (Free State Department of Health 2015b)
2. Free State Department of Health Annual Report 2015/2016 (Free State Department of Health 2016a)
3. Free State Thabo Mofutsanyana District Report (Health System Trust n.d.)
4. Thabo Mofutsanyana Service Transformation Plan (Free State Department of Health 2014)
5. Free State Department of Health Rehabilitation Policy guidelines (Free State Department of Health n.d.)
6. Free State Department of Health Occupational Therapy policy draft (Free State Department of Health 2013)
7. District Health Plan 2016/2017 (Free State Department of Health 2015a)
8. The Primary Health Care Package for South Africa - a set of norms and standards (Department of Health 2000b)
9. Community Operation Manual (Beukes *et al.* 2006)
10. Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020 (Department of Health 2015a)
11. National Rehabilitation Policy (Department of Health 2000a)

4.2.2. Discussion of data obtained

The full document review is available as Annexure C. A summary of the completed document review is given in Table 4.1:

Table 4.1: Summary of the findings from the document review		
Information Sought	Information Found	Source document
<u>Structural factors</u> regarding the relevance of the current regulatory documents		
Inclusion of occupational therapy in relevant policy and legislation (cf. 4.2.2.1.)	Occupational therapy is not mentioned and does not form part of the multi-disciplinary outreach teams	<ul style="list-style-type: none"> • Thabo Mofutsanyana Service Transformation Plan
	No specific mention is made regarding the inclusion of occupational therapy on PHC level or how occupational therapy services will be integrated into the PHC system	<ul style="list-style-type: none"> • Free State Department of Health Strategic Plan 2015/16-2019/20 • Free State Department of Health Annual Report 2015/2016 • Free State Thabo Mofutsanyana District Report • Thabo Mofutsanyana Service Transformation Plan • District Health Plan 2016/2017 • The Primary Health Care Package for South Africa - a set of norms and standards • Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020
<u>Procedural factors</u> that influence the rendering of occupational therapy services		
Effectiveness of rendering occupational Therapy services within PHC (cf. 4.2.2.2.)	Information on occupational therapy service delivery Included in the documents	<ul style="list-style-type: none"> • The National Rehabilitation Policy • Free State Rehabilitation Policy Guidelines • Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020
	Human and financial resource constraints are factors that will influence the rendering of occupational therapy service delivery	<ul style="list-style-type: none"> • Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020
	The ideal core rehabilitation team does not exist on PHC level	<ul style="list-style-type: none"> • Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020

This section will provide a summary of the data obtained as well as a discussion regarding its relevance towards the provisioning of occupational therapy services to stroke survivors within the PHC setting in the TMHD. This section will further identify the specific structural and procedural factors that will influence the design of an occupational therapy stroke program for the PHC setting.

4.2.2.1. Inclusion of occupational therapy in relevant policy and legislation

This section of the document review will focus specifically on the **structural factors** relating to the inclusion of occupational therapy in relevant public healthcare policies and documents. The term **structural factors** indicates the capacity of the health care provider under study (occupational therapy services within the TMDH) in terms of its facilities, resources and systems (Qu *et al.* 2010, p.48; Agency for Healthcare Research and Quality 2011). The document review has indicated that the FSDoH supports the concept of PHC re-engineering (cf. 2.2.3.) as a means of improving access to PHC services in the province (Free State Department of Health 2015b, p.22). The *Thabo Mofutsanyana District Service Transformation Plan* asserted that PHC will be the fundamental approach for the delivery of health care services in the district. The transformation plan also prescribed that multidisciplinary outreach teams must be established to conduct home visits (Free State Department of Health 2014, pp.6, 15).

Despite the FSDoH and the TMHD supporting the concept of PHC re-engineering, not all healthcare personnel are included in the transformation plan of the TMHD. The occupational therapist (as well as any other rehabilitation professionals) is **not** mentioned and **does not form part of the multidisciplinary outreach teams** (Free State Department of Health 2014, pp.55, 56). Overall, the document review found that seven out of the eleven public health care documents lack any reference to the inclusion of occupational therapy services on a PHC level. This stands in stark contrast to *The National Rehabilitation Policy* that states that rehabilitation personnel (including the occupational therapist) should be included in the PHC team (Department of Health 2000a, p.13). This document review, however, highlighted the fact that the occupational therapist is **not** considered when service delivery planning is done for PHC in the TMHD.

In addition, the *FSDoH's Annual Report of 2015/2016* specifies that rehabilitation services will be a strategic goal area to improve access to patients but only mentions one section of rehabilitation services, namely orthotic and prosthetic services. The report further focuses on improving access to rehabilitation services; however, it only focuses on the strengthening of human resources, again only for orthotic and prosthetic services. Rehabilitation services, however, comprise of more service elements than just the orthotic and prosthetic services (Department of Health 2015a, p.19).

The reality of occupational therapy being excluded from policies on a district and provincial level is unfortunately also true on a national level. *The Primary Health Care package of SA* ignores the inclusion of the occupational therapist in the rendering of PHC services to all patients. The package only indicates that the occupational therapist is included in the clinic specialist team in PHC for mental health care services (Department of Health 2000b, p.54).

According to the researcher, the occupational therapist can offer services to many other patient population groups and the value of occupational therapy services for PHC is not recognized or supported by relevant national policies and documents.

It is simply a fact that occupational therapy is excluded from the majority of relevant public healthcare documentation. This is a concern for rehabilitation personnel who are employed in the public sector. The *Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020* stated that there are no indicators available for rehabilitation outcomes within PHC and that rehabilitation services are not included into priority programs (such as non-communicable disease programs) of the NDoH (Department of Health 2015a, p.8).

The lack of the inclusion of occupational therapy (and other rehabilitation professions) is also acknowledged by Dayal (2010, p.26) who stated that the National Rehabilitation Policy has had very little effect to drive change within PHC. Draper, Draper and Bresick (2014, p.4) highlighted poor policy implementation in the management of chronic diseases on PHC level and that chronic patients experience poor access to allied health

services. Le Roux and Couper (2015, p.440) further deplore the fact that the goal of rendering comprehensive services on a PHC level remains barely achieved.

The **lack of the inclusion of occupational therapy in relevant public healthcare documentation** (on a national, provincial and district level), represents a factor that will influence the feasibility and design of an occupational therapy stroke program as it compromises the effectiveness of occupational therapy services to stroke survivors within the PHC setting. According to the researcher, the exclusion of occupational therapy in relevant policy and legislation will negatively impact on the support that a stroke program will receive from managerial structures in the TMHD and also the FSDoH, should such a program be designed and implemented.

As occupational therapy is not mentioned in relevant policies, it can be expected that **stakeholders within PHC will not recognize and support the enrollment of an occupational therapy stroke program** as current policies are not even implemented correctly and effectively (Draper, Draper and Bresick. 2014, pp.6, 7). The exclusion of occupational therapy will further have an **impact on the provisioning of possible human and financial resources** to implement such a stroke program, as PHC is already experiencing human resource and financial constraints (Dookie and Singh 2012, p.2; Draper, Draper and Bresick. 2014, p.6; Occupational Therapy Association of South Africa 2017, p.54).

In summary, the **exclusion of occupational therapy in the policies and legislation for PHC service delivery**, as well as the **exclusion of the occupational therapist as part of the multidisciplinary outreach team**, are vital factors that will influence the design of an occupational therapy stroke rehabilitation program as it will have an impact on the feasibility and support that such a program will receive from the relevant managerial structures.

4.2.2.2. Effectiveness in the rendering of occupational therapy services within PHC

While the previous section focused on the structural factors that will influence the design of an occupational therapy stroke program for the PHC setting, this section will focus on

the **procedural factors** that influence the rendering of occupational therapy services. The term **procedural factors** indicates the rehabilitation interventions, preventative and patient education activities (Qu *et al.* 2010, pp.48, 49) that form part of occupational therapy service delivery in the TMHD. This section of the document review, therefore, will attempt to identify these procedural factors in the relevant policy and legislative documents. However, as the previous section indicated, occupational therapy service delivery within PHC was scantily mentioned and no information regarding these procedural factors was found in the reviewed documents.

Although no information was found on the specific procedural factors, influential aspects of procedural factors were mentioned. Of the reviewed documents that focus specifically on PHC re-engineering only three documents included aspects of occupational therapy service delivery within PHC. These documents were *The National Rehabilitation Policy*, *Free State Rehabilitation Policy Guidelines* as well as the *Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020*. According to these documents, the procedural factors pertaining to the rendering of occupational therapy services are directly influenced by the structural factors that were mentioned in the previous section (cf. 4.2.2.1.). The *Framework and Strategy for Disability and Rehabilitation Services in SA* reported a high vacancy rate amongst rehabilitation officials in the PHC (Department of Health 2015a, p.9) and occupational therapy rehabilitation interventions and the **provisioning of services are directly influenced by these human resource constraints**. Although the high vacancy rate is not a new phenomenon in PHC (Lehmann 2008, p.174), it undoubtedly adds to pressure on scarcely employed health care professionals who are required to provide in the needs of the growing patient population. This raises questions, as stated in the literature review (cf. 2.3.3.; 2.4.2.), regarding the effectiveness of the current model of occupational therapy service delivery to stroke survivors within the PHC setting.

The *Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020*, further indicated that the procedural factors relevant to the rendering of occupational therapy services are not only influenced by human resource constraints. Financial constraints together with **inadequate follow-up of patients, poor referral**

pathways and inadequate provisioning of assistive devices also influence these services (Department of Health 2015a, p.8). The ability of patients to access services on PHC level remains a challenge and the access to services are further compromised by the non-existence of the ideal core rehabilitation team (Department of Health 2015a, p.8). All these factors have a negative influence on the procedural factors that will influence the design and effectiveness of an occupational therapy stroke program for the PHC setting.

Not only are occupational therapy services infrequently available at PHC clinics (cf. 2.3.3.; 2.3.3.1.), but the *Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020* also indicated that **rehabilitation personnel display a lack of awareness of the challenges that people with disabilities face** (Department of Health 2015a, p.8). These challenges include inaccessible and unaffordable transport, therapy not being provided in the mother tongue as well as poor cultural sensitivity by rehabilitation staff (Naidoo, Van Wyk and Waggie. 2017, pp.41, 42; Department of Health 2015, p.8). These are also aspects to consider as impacting on the procedural factors of occupational therapy service delivery within the PHC setting as it may negatively influence the effects of occupational therapy services (cf. 2.4.2.) and the rehabilitation of the stroke survivor. It will undoubtedly also influence the design of an occupational therapy stroke rehabilitation program for the PHC setting.

Human resource constraints, inadequate follow-up of patients, poor referral pathways, inadequate provisioning of assistive devices as well as a lack of awareness amongst rehabilitation personnel regarding the challenges that people with disabilities face, are all factors that will influence the procedural aspects in the design of an occupational therapy stroke rehabilitation program. Although some of these factors are structural in nature, it will undoubtedly have an impact on the procedural factors. These factors should, therefore, be carefully considered to ensure that it constitutes no barrier to the feasibility of an occupational therapy stroke program for the PHC setting. This section further raised questions regarding the effectiveness of the current occupational therapy service delivery due to **lack of outcome measures for occupational therapy in the relevant policy and legislation**. The inadequate human

and financial resources for occupational therapy services, as well as the questionable effectiveness of these services, are thus of great concern and innovative ways of thinking are needed to overcome these barriers when designing an occupational therapy stroke program for the PHC setting. It is recommended by the researcher that more efficient ways of service delivery, rather than one-on-one therapy, be explored in order to make services more freely available to more patients even with fewer human resources available.

4.2.2.3. Conclusion

In conclusion, it is evident from the document review that structural and procedural factors will influence the design of an occupational therapy stroke program for the PHC setting. The structural factors include the exclusion of occupational therapy in relevant policies and documentation as well as the poor availability of human and financial resources, while the procedural factors include inadequate follow-up of patients, insufficient referral pathways and inadequate provisioning of assistive devices. It was also noted that the structural factors influence the procedural factors and that this raises questions regarding the effectiveness of current occupational therapy service delivery models within PHC. All of these factors will influence the design as well as the relevance and feasibility of an occupational therapy stroke program for the PHC setting.

4.3. STRUCTURED CLINIC OBSERVATIONS

The researcher executed structured clinic observations at PHC clinics in the TMHD with the aim of identifying the structural factors that will influence the design of an occupational therapy stroke program for PHC. These structural factors relate specifically to the physical environment that is available to render occupational therapy services to stroke survivors within the PHC setting.

4.3.1. Demographic information

A total number of seven (n=7) PHC clinics were visited in the TMHD. At least one clinic was visited per sub-district in order to represent the whole TMHD. The purposefully

chosen clinics were at the time of the research, all being visited by occupational therapy staff for outreach services and were thus used by stroke survivors on a regular basis.

4.3.2. Accessibility of the Primary Health Care Clinics for stroke survivors

The accessibility of the PHC clinics for use by stroke survivors was observed by means of a structured observation checklist. Table 4.2 indicates the results from the data obtained that relate specifically to the accessibility of the PHC clinics:

Table 4.2: Accessibility of PHC clinics in the TMHD for stroke survivors		
Accessibility component	Percentage	n=7
There is a passenger drop-off zone adjacent to the accessible entrance of the clinic	57.4%	4
The entrance is level or has a ramp with a gradient of 1:12 (degree of slope of 4.80)	28.57%	2
Passages and thoroughfares are wide enough for passage of wheelchairs even when busy	28.57%	2
Floor surfaces are not slippery when wet	14.29%	1
Lights in passages are in a working condition	57.14%	4
At least one unisex toilet designated for people with disabilities in the public area	85.71%	6
Larger toilet cubicle size with an outward opening door (>1500mm x 1500mm clear space for a wheelchair to turn)	57.14%	4

It is evident, when examining Table 4.2, that **not one of the PHC clinics in the TMHD fully meet the minimum standards of accessibility for people with disabilities**. This is a major factor that need to be taken into consideration when designing an occupational therapy stroke program for PHC as it implies that stroke survivors who are making use of wheelchairs or who have difficulty in ambulation, will find access to the clinics challenging.

Although the challenge of poor accessibility of PHC clinics in the TMHD, to the knowledge of the researcher, has not been documented yet in formal scientific

literature, this challenge is not new in the broader South African context. The *Framework and Strategy for Disability and Rehabilitation services in SA* maintained that one of the priority goals that need to be addressed regarding the delivery of rehabilitation services to people with disabilities, is the implementation of accessibility standards for public sector facilities (Department of Health 2015a, p.17). A study on the accessibility of rural healthcare services in the Eastern Cape province of SA found that the public health care facilities were poorly designed and not wheelchair friendly for people with disabilities (Vergunst *et al.* 2015, p.5). Although the information from this study shows interesting similarities with the results found in the current study, the information could not be generalized to the TMHD population due to differences in geographical areas as well as population differences.

A study carried out in the United States, although it cannot be generalized to SA, also offers some interesting similarities to the current study with regards to the accessibility of primary healthcare services for wheelchair users. The study found that the clinics were most often inaccessible to wheelchair users due to inaccessible passages and bathrooms (Stillman *et al.* 2017, p.3). This correlates with the results from the current study and therefore the problem of inaccessible PHC clinics are not a unique problem to the TMHD, but refers to a global problem experienced by people living with disabilities.

The inaccessibility of PHC clinics and the facilities thereof is an important factor to take into consideration when designing an occupational therapy stroke program for the PHC setting as the majority of stroke survivors in SA (and in the TMHD) are dependent on receiving healthcare services at a PHC clinic. These structural factors, therefore, need to be considered and should include the **inaccessibility of entering and moving around** in the clinics as well as the **accessibility of the bathrooms** as these are vital factors that will influence the feasibility of such a program.

4.3.3. Feasibility of rendering occupational therapy services at Primary Health Care Clinics

The structural observation checklist further investigated the procedural factors that will influence the design of an occupational therapy stroke program for PHC. Table 4.3

summarizes the results for the feasibility of rendering occupational therapy services at PHC:

Table 4.3: Feasibility of rendering occupational therapy services within PHC clinics		
Feasibility component	Percentage	n=7
Individual treatment space		
There is a private space available for individual occupational therapy treatment - a separate room with a closing door	71.43%	5
The size of the treatment space is at least 36m ²	0%	0
Therapy equipment such as a NDT-plinth, mirror and radio is available in the treatment space	0%	0
The treatment space offers a basin with running water	57.14%	4
Group treatment space		
The clinic offers an open space for group therapy	14.29%	1

The results depicted in Table 4.3 focuses mainly on the availability of space to render therapeutic services. It is evident from the results that the rendering of occupational therapy services (as well as other rehabilitation services) was not kept in mind in the design and structural planning of the PHC clinics. The examination rooms that are used by occupational therapists at PHC clinics were designed for medical officers and nurses. The **rooms are generally very small** and only offer an examination bed, desk, and chair. The results indicated that **no equipment is available at clinics** to render rehabilitation services and this is supported by a study completed in the Western Cape province of SA that stated that equipment within PHC for use by rehabilitation personnel is limited (Mlenzana and Frantz 2017, pp.249, 252).

None of the clinics observed met the minimum criteria for individual occupational therapy treatment space of 36m². In most of the rooms, **the space is not adequate for a wheelchair to enter and turn in the room**. Despite these shortcomings, therapists are still required to offer their services.

Limited space in PHC clinics is a definite structural factor that will influence the design of an occupational therapy stroke program. The small and inaccessible rooms raise the question whether the rendering of individual occupational therapy services in the TMHD

can be efficient and whether the needs of stroke survivors are met within this setting. Since this topic has not been investigated in the Free State, these questions remain unanswered. However, it calls to strengthen the need for re-evaluating and re-engineering occupational therapy services within PHC for stroke survivors through future research.

Another factor that will also influence the design of an occupational therapy stroke program for a PHC setting is the **lack of space to render group therapy at the clinics**. Group therapy falls within the scope of occupational therapy services within the PHC setting (cf. sections 2.3.1. and 2.3.3.). It is however, depicted in Table 4.3, a fact that clinics do not offer any space or equipment for group therapy at the PHC clinics in the TMHD.

Limited space for the rendering of both individual and group therapy, together with the **unavailability of equipment** at the PHC clinics, are structural factors that will undoubtedly influence the feasibility of an occupational therapy stroke program for the PHC setting as it will have an impact on where and how such a program is designed.

4.3.4. Conclusion

The structural observation checklist highlighted a number of important factors that should be kept in mind in the design of an occupational therapy stroke rehabilitation program for PHC. These factors include the inaccessible clinic entrances and passages as well as the inaccessible bathrooms designated for people with disabilities. Other factors include the lack of proper space to render individual and group therapy as well as the lack of equipment at PHC clinics. The need to explore innovative ways to address these challenges is undoubtedly raised.

4.4. STRUCTURED INTERVIEWS WITH COMMUNITY HEALTH CARE WORKERS

Structured interviews with CHWs were conducted with the aim of identifying the procedural factors that need to be considered when designing an occupational therapy stroke program for PHC. The procedural factors for this section relate specifically to the multidisciplinary teams' understanding of the occupational therapist's roles when

rendering services to stroke survivors within the PHC setting. This section also includes the perspectives of the CHWs on the challenges that stroke survivors experienced while receiving occupational therapy services.

4.4.1. Demographic description of participants

A total number of 32 (n=32) CHWs participated in the study of which 30 (93.75%) were females and only two (6.25%) were male. The median age for the participants was 39 years with the minimum and maximum age at respectively 27 and 59 years of age. The majority of the participants (59.38%; n=19) were employed by non-governmental organizations while only 15.63% (n=5) of participants were employed by the Department of Health at the time of data collection.

The median years of experience in working as a CHW in the TMHD were seven years, while the median duration of working with stroke survivors in the TMHD was six and a half years. An astonishing 96.88% (n=31) of participants indicated that they are rendering services at patients' homes, while only 46.88% (n=15) of the participants also render their services at the PHC clinics.

4.4.2. Procedural factors relating to the understanding of the CHWs on the roles of the occupational therapist

During the interviews, participants were asked which rehabilitation officials are available in their area to render services to stroke survivors and 40.63% (n=13) of the participants indicated that a physiotherapist is available to assist CHWs with stroke survivors. A problematic 31.26% (n=10) of participants indicated that there is either no rehabilitation official or they do not know of any rehabilitation official and only 9.38% (n=3) of the participants indicated that an occupational therapist is available. Since there are occupational therapists (and physiotherapists) who are employed in each sub-district of the TMHD, this can be seen as problematic as it indicates **a lack of knowledge and awareness** amongst CHWs regarding the rehabilitation services that can be offered/are available on a PHC level.

This is a factor that needs consideration when designing an occupational therapy stroke program for PHC, as the CHWs are often the first line of contact with stroke survivors in their homes. It will be essential for CHWs to understand the full scope of practice, especially of occupational therapy, ensuring the referral and the implementation of a stroke program that is implemented accurately within PHC and communities.

Although the majority of CHWs were not aware of the availability of occupational therapy services, 25 participants (78.13%) indicated that they know how to refer stroke survivors to an occupational therapist, while 40% (n=10) of these participants indicated that they are referring their stroke survivors (in need of occupational therapy) to the clinics for further referral by the clinic nurses. The *Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020* (Department of Health 2015a, pp.8, 9) lamented the **poor referral pathways** for rehabilitation. The effectiveness of referrals from CHWs can, therefore, be questioned as a large number of participants indicated that they do not have access to referring directly to occupational therapy.

A total of 62.50% (n=20) participants claimed that they know which services an occupational therapist render, but when asked to elaborate on the services, 70.00% (n=14) of the participants declared that occupational therapists assist with exercises and training while 20.00% (n=4) said that occupational therapists assist with walking. This is a call for concern as it clearly demonstrates that CHWs are **not aware of the full-service package** that occupational therapists can render to stroke survivors within the PHC context. According to the *Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020*, the occupational therapist *helps individuals achieve independence in all facets of their lives* (Department of Health 2015a, p.19) and thus the scope of occupational therapy is much broader than only providing exercises and training. The possibility that the CHWs confuse the scopes of occupational therapy and physiotherapy can also not be excluded.

The **lack of knowledge** amongst the CHWs is supported by a study executed with CHWs and PHC nurses in the KwaZulu-Natal province of SA. It was found that role-players within PHC observed the occupational therapist as providing services from a

medical model with very little community engagement (Naidoo, Van Wyk and Joubert 2016, p.6), indicating that occupational therapists are not necessarily visible within the PHC setting. This is a factor that needs consideration in the design of an occupational therapy program as it will influence the relevance and content of such a program.

As part of the questionnaire, CHWs were asked if they would be willing to present a program to stroke survivors in the community if they are trained by an occupational therapist. An astonishing number of 96.88% (n=31) of the participants indicated that they would be willing to present a structured program to stroke survivors in the PHC setting. On a question if they would prefer to present such a program either individually, in a group or both, 50.00% (n=16) of these participants indicated that they would want to present such a program in a group setting due to a number of reasons. These reasons included that stroke survivors can help and motivate one another when they get to know one another better; that the information can be taken to a lot of people; that they can support one another; that it is easier to reach stroke survivors in a group, and it will save time as it takes a lot of time to treat stroke survivors individually. The CHWs who indicated that they would prefer to present such a program individually, stated that they are attending to households; therefore, individual programs are easier and some stroke survivors prefer to be seen alone.

Very little information or previous research is available on the CHWs' comprehension of the role of occupational therapy for stroke survivors; especially in the Free State. This is the first study, to the knowledge of the researcher, to explore the relationship between CHWs and occupational therapists in the TMHD. An unpublished study in the TMHD examining the perceptions of CHWs on physiotherapy found that CHWs had little or no knowledge regarding physiotherapy and the CHWs requested training and support by physiotherapists in the field of physiotherapy as well as how to enhance service to patients and their families (Lowe 2015, pp.62–68, 99, 105).

A lack of knowledge amongst CHWs regarding the full-service package that occupational therapy can offer as well as the **poor referral pathways**, are procedural factors that need to be taken into consideration when designing an occupational therapy

stroke program for the PHC setting. These factors will not only influence the content and composition of such a program, but it will also influence the feasibility thereof

4.4.3. Procedural factors that are essential in ensuring occupational therapy intervention for stroke survivors are relevant and feasible.

As part of the questionnaire, CHWs were asked what aspects need to be addressed when providing occupational therapy services to stroke survivors. The question was not only directed towards chronic stroke survivors, but also acute stroke survivors. Figure 4.1 indicates the aspects that are considered important by the CHWs:

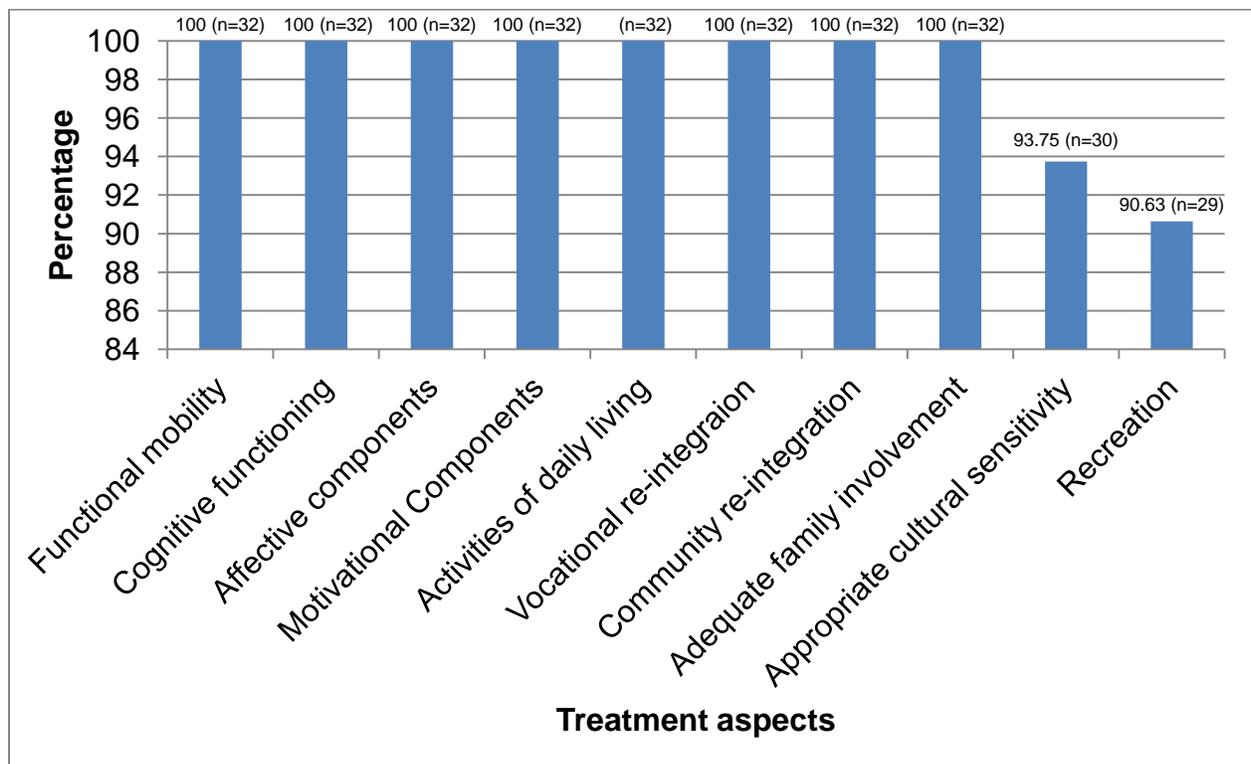


Figure 4.1: Occupational therapy treatment aspects that need to be rendered to stroke survivors

As described in section 4.4.2., it was evident that CHWs are not aware of the full-service package that occupational therapists can offer to stroke survivors. From Figure 4.1 it is clear that CHWs, although not well informed on the advantages of occupational therapy, indicated that stroke survivors can benefit from a number of services that can be rendered by the occupational therapist (cf. 2.4.1.). Wolf, Baum and Connor (2009,

pp.624) indicated that the rehabilitation of stroke survivors largely overlooks employment and that the focus of the rehabilitation of stroke survivors should not end with acute stroke management. Wolf, Baum and Connor (2009, pp.624, 625) also added that focus should be placed on the stroke survivor's ability to return to work, indicated as vocational re-integration in Figure 4.1. This calls for **education and advocacy** by occupational therapists amongst health care staff to **demonstrate services that can be rendered by occupational therapists** as well as the potential benefits of these services to, particularly, stroke survivors. Naidoo, Van Wyk and Joubert (2017, p.8, 9) argued that people with disabilities (living in rural areas) are in definite need of more occupational therapy services that are adequate and appropriate in addressing their needs, especially with regards to activities of daily living. Occupational therapists are certainly equipped to address these needs and this strengthens the call for education and advocacy amongst health care staff.

The **lack of knowledge** amongst CHWs regarding the services that can be rendered by the occupational therapist is a procedural factor that will influence the relevance and feasibility of a stroke program in PHC. This section further emphasized that CHWs indicated that stroke survivors will benefit from the range of occupational therapy services within the PHC setting.

4.4.4. Structural factors regarding the physical environment available to render occupational therapy services to stroke patients within the PHC setting.

During the interviews, CHWs were requested to indicate where a stroke program could best be presented. Figure 4.2 indicates the responses of the CHWs:

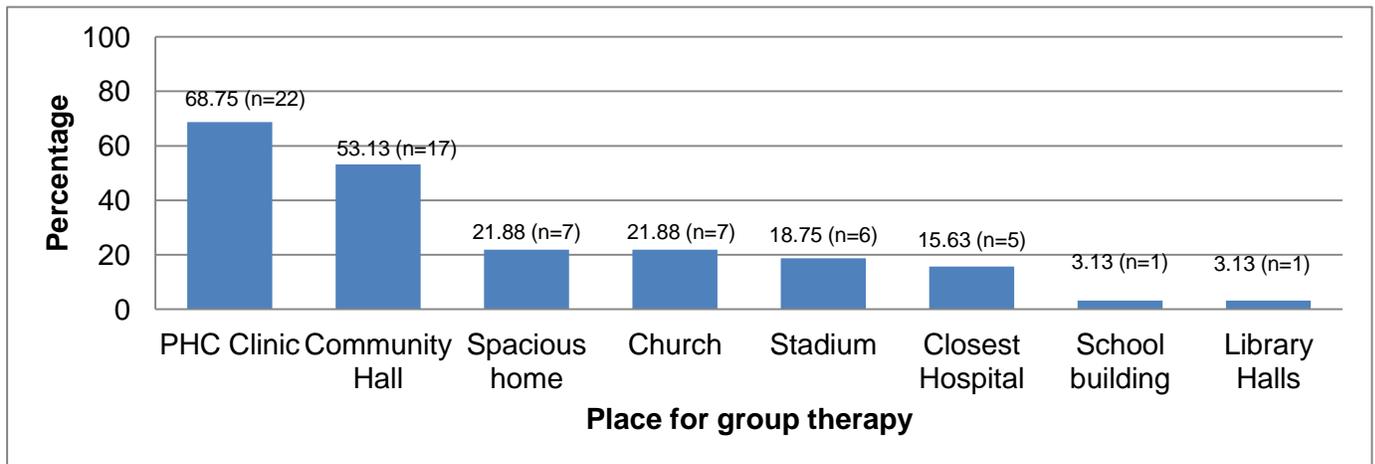


Figure 4.2: Ideal venue to host a stroke program in PHC

The majority of the CHWs indicated that a stroke program would be best hosted at either a **PHC clinic** (68.75%, n=22) or a **community hall** (51.13%, n=17). However, evidence from section 4.3.3. clearly underscores the fact that PHC clinics are not ideal to present such a program as they do not offer adequate space for group or individual therapy. The possible use of community halls implies that it would be wise to include other sectors, such as the local government (also known as district municipalities), in the design of an occupational therapy group program within a PHC setting.

Intersectoral collaboration can be explored during phase two of the DSR process (cf. Figure 3.1) in the future. This can be done on a district management level as the inclusion of local government falls within the scope of the DHS of PHC (c.f. 2.2.3.).

4.4.5. Challenges faced by stroke survivors who seek occupational therapy services within PHC

The structured interviews further sought to explore how the CHWs view the challenges that are experienced by stroke survivors when they are seeking occupational therapy services within the PHC setting. The most prevalent challenges that stroke survivors experience within the community, according to the CHWs, are indicated in figure 4.3:

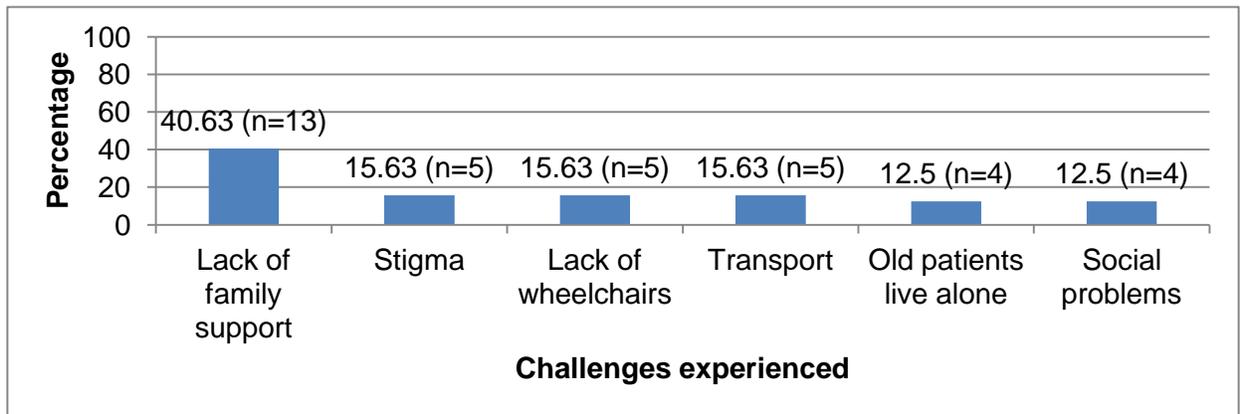


Figure 4.3: Challenges experienced by stroke survivors from a CHWs perspective

Figure 4.3 illustrates that CHWs perceive that stroke survivors are experiencing a number of challenges. The CHWs (40.63%, n=13) indicated that the biggest challenge stroke survivors experience is due to the lack of family support. In addition to these challenges, they also stipulated the challenges that stroke survivors experience in accessing rehabilitation services. Figure 4.4 indicates the most prominent barriers identified by the CHWs.

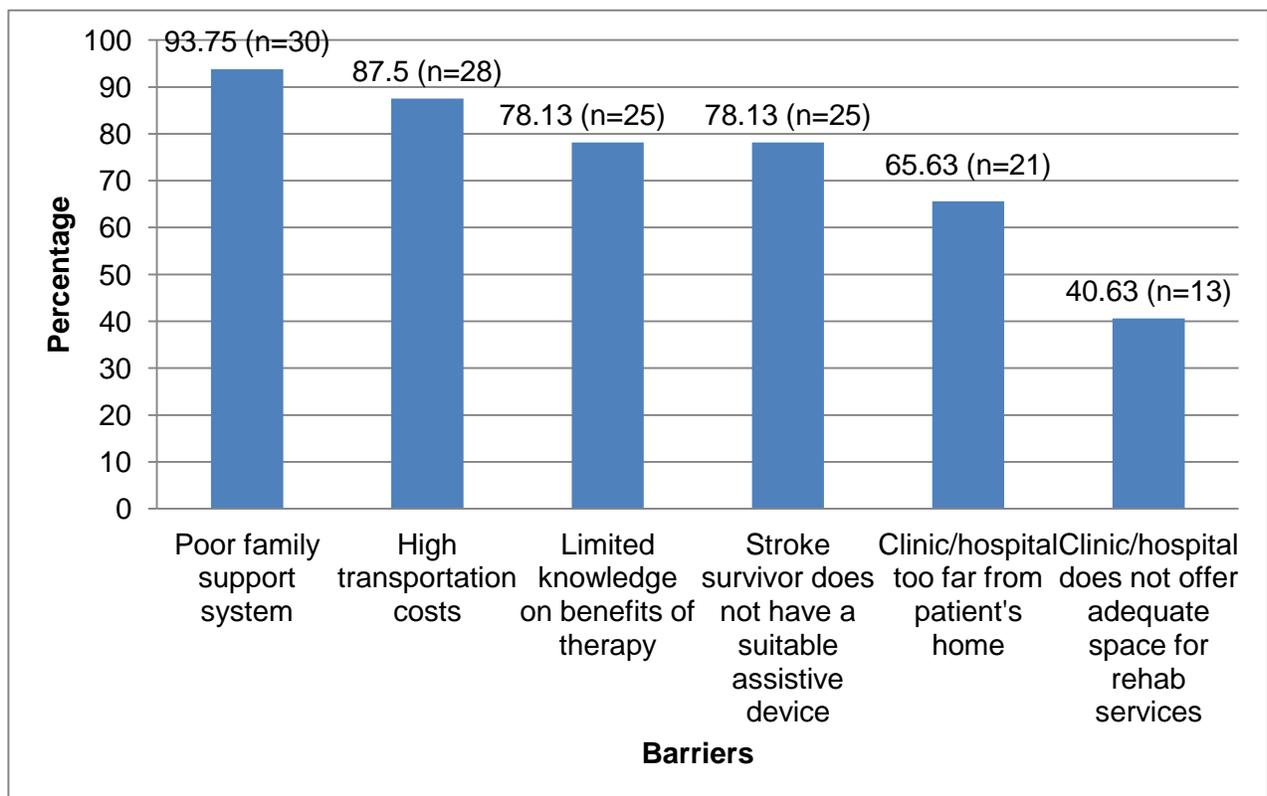


Figure 4.4: Challenges experienced by stroke survivors in accessing rehabilitation services in PHC

As mentioned in Chapter 2 (cf. 2.4.3.) and supported by the results from the interviews with the CHWs, stroke survivors are burdened with a number of challenges. CHWs work closely with stroke survivors in their homes and communities and they have identified the most prominent challenges for stroke survivors as, firstly, that of a **poor family support system (93.75%, n=30)** and secondly, **high transportation costs (87.50%, n=28)**. **Limited knowledge on the benefits of therapy (78.13%, n=25)** and **not having a suitable assistive device (78.13%, n=25)** were also identified as some of the top challenges.

In comparison with the current study, results from a study conducted in a rural area in the KwaZulu-Natal Province of SA, indicated that CHWs identified similar challenges and barriers for people with disabilities who are accessing occupational therapy services within PHC. Difficulties in accessing and affording transport were highlighted and it was also stated that people with disabilities are often abused, discriminated against or marginalized (Naidoo, Van Wyk and Joubert 2017, pp.6, 7). Naidoo, Van Wyk and Joubert (2017, pp.7, 8) further added that CHWs reported that people with disabilities are often abused by their own families and often these people are locked-up and isolated from their families and communities. In this study, people living with disabilities have indicated that they are in need of more appropriate wheelchairs that are fit for the rural setting (Naidoo, Van Wyk and Joubert 2017, p.8). In unpublished work done in TMHD by a physiotherapist, Lowe (2015, p.103) also indicated that CHWs identified that they often do not refer patients to physiotherapy because the patients do not have any transportation to access the service.

It is evident from literature as well as from the results of the current study that stroke survivors are facing a number of challenges. **Poor family support systems** and the **lack of access to transportation** to attend therapy sessions were the two most prominent challenges. These challenges are major factors that need to be considered when designing an occupational therapy stroke program in a rural PHC setting as it will have an influence on the feasibility of such a program. These factors need to be carefully considered and solutions should be sought to overcome these challenges. Overcoming these barriers is essential in ensuring that a designed program for stroke

survivors in PHC is relevant, feasible and accessible to allow stroke survivors to actively engage in such a program.

4.4.6. Conclusion

The CHWs added valuable insights into the factors that need to be considered when designing an occupational therapy stroke program for the rural PHC setting. These factors include a lack of knowledge amongst the CHWs regarding occupational therapy services to stroke survivors, poor referral pathways and a number of challenges that stroke survivors are experiencing including poor family support systems, high transportation costs, the availability of suitable assistive devices and limited knowledge of occupational therapy by the survivors themselves. All of these procedural, structural and challenge factors should be considered when designing an occupational therapy stroke program for the PHC setting to ensure its relevance and feasibility.

4.5. FOCUS GROUP WITH OCCUPATIONAL THERAPISTS

The methodology of collecting data for the focus group was discussed in detail in the previous chapter (cf. 3.4.5.). The focus group sought to answer all of the objectives for this research study from the perspectives of occupational therapists who are permanently employed in the TMDH. This section will provide a brief overview of the participants of the focus group where after the findings of the focus group will be presented in the form of themes, categories and codes. The findings will also be discussed in the context of relevant literature.

4.5.1. Description of participants

A total of four female participants (out of six eligible participants) took part in the focus group. The participants were all occupational therapists who were permanently employed by the FSDoH at the time of the study. All the participants were based at district hospitals in the TMHD and all of them had experience in rendering occupational therapy services to stroke survivors within a rural PHC setting. The experience of the occupational therapists ranged from a minimum of four years to a maximum of 22 years. None of the occupational therapists had any postgraduate qualifications at the time of

the study. All six of the eligible participants were white and Afrikaans speaking, however, the focus group was done in English as it is the official language of communication in the FSDoH.

4.5.2. Presentation and interpretation of data

The findings from the focus group will henceforth be discussed. The researcher will make use of verbatim quotes from the focus group and the findings will be presented according to themes, categories and codes as discussed under section 3.8.6. Verbatim quotations are presented exactly as they were spoken, without correcting any language errors, so as to not lose any of the original meaning. The verbatim quotes include some language and grammatical errors as English was the second language for all of the participants (cf. 3.4.5.3.).

The researcher will indicate the number of the participant (e.g. P1) with each verbatim quote in order to provide evidence that the data used was representative of all the participants in the focus group. Creswell's method of data analysis was used (*Botma et al. 2015*, pp.223–225) to analyse and interpret the data. Triangulation will be used by means of comparison with existing literature as well as with findings from other data sets from the current study. The use of triangulation is used to indicate a high construct validity of the data obtained through the focus group (*Botma et al. 2015a*, p.176).

Table 4.4 presents a layout of the themes, categories and codes in order to guide the reader on the content that will follow. During the analysis of the focus group, four primary themes were identified, namely: structural factors, procedural factors, the PHC client and suggestions. It is noteworthy to mention that all of the objectives of this study were addressed in the data obtained from the focus group. Each of the themes will henceforth be discussed with its individual categories and codes. After the description of the codes for each category, a summary of the findings for that category will follow.

Research Question	Themes	Categories	Codes
What are the factors that will influence the relevance and feasibility in the design of an OT program for stroke patients within a rural PHC setting in the THDH?	4.5.3. Structural Factors	4.5.3.1. Facilities	a) PHC Clinics
		4.5.3.2. Resources: Human	a) The occupational therapist
			b) Multi-disciplinary team
			c) CHWs
		4.5.3.3. Resources: Non-Human	a) Finances
			b) Transport
		4.5.3.4. Systems	a) Policies
	b) Communication		
	4.5.4. Procedural Factors	4.5.4.1. Interventions (role of occupational therapy)	a) Acute Rehabilitation
			b) Group intervention
			c) Home visits
			d) Cultural competency
		4.5.4.2. Education and support	a) Family education
	4.5.5. The PHC Client	4.5.5.1. Client characteristics	a) Personal characteristics
			b) Awareness of occupational therapy role
		4.5.5.2. Challenges	a) Accessing therapy
			b) Family life
	4.5.6. Suggestions	4.5.6.1. Human Resources	a) Therapy staff
b) Group therapy and CHWs			
4.5.6.2. Non-human resources		a) Mobile rehab clinic	
		b) Care centres	
		c) Resources for occupational therapy	

4.5.3. STRUCTURAL FACTORS

The theme of structural factors strongly surfaced during the focus group and this theme has a definite impact on the design of an occupational therapy stroke program for the PHC setting to ensure its relevance and feasibility. A total number of four categories were identified for structural factors that included facilities, human resources, non-human resources and systems. Each category will be discussed together with its codes.

4.5.3.1. Facilities

Themes	Categories	Codes
4.5.3. Structural Factors	4.5.3.1. Facilities	a) PHC Clinics

Facilities form a major part of the structural aspects that need to be considered when rendering occupational therapy services to stroke survivors in PHC. It is crucial to take facilities into account when factors that will influence the relevance and feasibility of an occupational therapy stroke program for PHC are considered. The suitability of the PHC facilities will determine where a stroke program can be presented.

a) PHC Clinics

During the focus group a concern was raised regarding the accessibility of the PHC clinics:

P1: So and most of them are very inaccessible, even the newly built ones. They are not accessible, and accessibility for me is not just having the toilet in the facility, it is also the roads and curbs, getting to the front door is a huge, huge thing.

P1: Accessibility is something that is so important and I know nationally they are trying but nobody cares about that because the budget is so limited and they have to do so much with it. If you have to choose between a ramp and medication, you will choose medication.

P1 stressed that it is **challenging for stroke survivors to access the PHC clinics**, in this case, mainly due to their physical structure. The issue of **budget constraints** for PHC was also highlighted and it was evident from the focus group that accessibility is not perceived as a priority when looking from a budget point of view. Although a lot of new PHC clinics have been built in the recent past, and are still being erected, it is clear

that accessibility for people with disabilities has been neglected. This shortcoming was also described in 4.3.2. The structured clinic observations (cf. 4.3.2.) further revealed that the bathrooms are inaccessible, ramps and curbs are not meeting the set criteria and the passages in the clinics are too narrow. The **poor accessibility of the clinics** may be a barrier to some stroke survivors and may lead to some survivors not being able to attend an occupational therapy stroke program if such a program were to be presented at PHC clinics.

It was not only the problem of accessibility that was a concern, but also the suitability of the clinic itself as a therapeutic space:

P2: ...there isn't enough space. Like rooms have to be shared between the Occupational Therapists and Physio and sometimes the Dietician as well.

P1: I think in all the smaller towns and basically all the Clinics, even the newly built ones rehab was not included. They didn't even think about rehab when they built that Clinic, so there is no, no space where you can treat a patient.

The participants voiced that they do not have **access to adequate space** within the clinics to offer occupational therapy services and often they are also required to share the small, available space with other healthcare professionals. This correlates directly with findings described in section 4.3.3. It was evident from the structured observations at the clinics that the therapy rooms do not meet the minimum space requirements for individual therapy. Furthermore, the therapists also voiced the lack of the availability of equipment at the clinics that was also stated in section 4.3.3.:

P2: So you don't have Neuro Plinths, you don't have any proper equipment that you would like to use with the rehab of that stroke patient. So there is a lot of structural problems, and they are barriers actually.

The findings from the clinic observations and the focus group correlate with a study that was done in the Western Cape province of SA. Mlenzana and Frantz (2017, p.249) indicated that patients with disabilities, who are receiving therapy at PHC institutions in the Western Cape, face challenges regarding the lack of space at the institutions and therapists are forced to use old equipment that is due for replacement. It is, therefore, evident that structural challenges, experienced by participants in the current study, are

not unique and that governing bodies are called upon to acknowledge these challenges and to assist in achieving solutions.

The inaccessibility of the PHC clinics as well as **the lack of equipment** are factors that need to be taken into consideration as it will influence the budget planning as well as the compilation of an occupational therapy stroke program.

b) Summary: Facilities

The structural barriers that occupational therapists experience at PHC clinics are definite structural factors that will influence the design of an occupational therapy stroke program for PHC. The clinics might not be the best suitable venues from which to render a stroke rehabilitation program and the lack of equipment may have financial implications in the possible future design and execution of such a program.

4.5.3.2. Resources: Human

Themes	Categories	Codes
4.5.3. Structural Factors	4.5.3.2. Resources: Human	a) The occupational therapist
		b) Multidisciplinary team
		c) CHWs

Another category, on which participants focussed strongly, was that of human resources. **Human resources** is an essential, non-negotiable structural factor ensuring that a stroke program for PHC will be feasible. No program can be presented without adequate human resources. From the category of human resources, three codes emerged, namely: the occupational therapist, the multidisciplinary team and the CHWs.

a) The occupational therapist

The participants in the group were very passionate about their roles as occupational therapists:

P2: ...so as a team there is always one person that is the motivator and the supporter and it is usually the Occupational Therapist.

P1: Because we are all very passionate and very loyal to what we do, and we really try our best but yes.

Although the participants were positive about their profession, a negative tone was also identified. Their negativity emanated from a range of challenges that they are experiencing in the daily execution of their duties. Firstly, therapists felt that they are suffering from a lack of support, even though they are walking the extra mile amid the known resource and budget constraints:

P2: I think I just would like to also mention that I think a lot of the Occupational Therapists are very resourceful and they take initiative, so I think a lot of times yes patients get treated and on patient level we can see that the impact that Occupational Therapists are making but, not with a lot of support. So I think a lot of Occupational Therapists are overworked and underappreciated. I think that is the two main things.

From the remark of P2 it is evident **therapists feel overworked** and that they have the **perception that their efforts are not supported and amply appreciated**. Secondly, due to the **lack of the adequate number of staff**, therapists are only based at hospitals. It is required of one therapist to cover all the patients in the hospital and to serve the PHC clinics on outreach visits as well:

P3: I think maybe at an institutional basis we can have a little bit more of the recognition for our role, that somebody actually says, you know what, these people are doing something good, let us try and help them with resources.

P2: all of us are based at a hospital, and from hospital you have to do in-patient and then still do outreach as well.

The fact that therapists are required to serve patients at the hospital and clinics, adds to their feeling of being overworked. A recent study indicated that rehabilitation staff members working within the PHC setting in the Western Cape of SA are "... stretched to the limit ..." due to staff shortages (Mlenzana & Frantz 2017, p.249). This supports the current finding.

Occupational therapists can offer significant value within the primary care setting as they assist in improving the function and participation of the clients that they see (Dahl-Popolizio *et al.* 2016, p.278). However, a study on job satisfaction amongst occupational therapists in the public health sector in the Free State, indicated that poor recognition systems, as well as inadequate resources, lead to job dissatisfaction (Swanepoel 2010, pp.234, 235). It is, therefore, crucial to ensure that the role of the occupational therapist within PHC is well understood and that occupational therapists are equipped to offer their full potential. This will prevent therapists from feeling overworked while an understanding of the value that occupational therapy can add to PHC settings, will be a motivating factor to employ more occupational therapy staff.

The **underprovision of occupational therapy staff** and the fact that therapists **feel overworked and underappreciated** are crucial structural factors that will influence the feasibility and the design of an occupational therapy stroke program for the PHC setting. These factors are vital to consider as it will influence the therapists' attitude and support towards such a program, however, the occupational therapists can also make valuable contributions to possible future research to ensure that these factors are addressed and/or compensated for in the design of such a program.

b) The multidisciplinary team

The majority of the participants stated that they provide therapy to their stroke survivors within a multidisciplinary team. Participants asserted that the use of multidisciplinary teams (MDTs) is a positive phenomenon within the PHC setting:

P2: I think most of us work in multi disciplinary with Physiotherapists or the Speech Therapist. I think in Primary Health we, we mostly work in teams, interdisciplinary where in private that is not the case. So I think we have an advantage of working inter disciplinary.

P3: ...we are very lucky we have a Speech Therapist that works with us in the team so we try to work interdisciplinary.

P2: ...sometimes we are understaffed and we do not have a Speech, we just have a Physio or whatever. And then it is negative in from the other side. Due to time limitations sometimes you are not able to see a patient as a team as, because the Physio has got I don't know how many patients so you have to see the stroke patient on your own because you can. So sometimes yes, staffing also plays a negative role on the Primary Health Care.

It is, however, also apparent that the use of the MDT is not a reality for all of the participants as some hospitals do not have full MDTs available, implying that the service is also not available at PHC level. Staffing norms are obvious challenges within the PHC setting. In line with this, the authors reporting on a study completed in the Western Cape of SA, argued strongly that a multi-professional team is crucial in ensuring that rehabilitation is effectively applied. Unfortunately, they found that the majority of the rehabilitation centres lacked an adequate number of allied healthcare workers (Mlenzana and Frantz 2017, p.251). This calls for a renewed emphasis on (particularly) human resources and staffing norms for the PHC setting. **Staffing norms** is an important **structural factor** that will influence the relevance and feasibility of the design of an occupational therapy stroke program for the PHC setting.

Although the use of the MDT in the TMHD was seen by the participants as a unique characteristic, it should be kept in mind that the full MDT is not always available and that stroke survivors often do not have access to all the rehabilitation services that they are in need of (cf. 2.2.4.; 2.4.2.; 4.4.5.). According to the knowledge of the researcher, no literature is available on the effectiveness and benefits of the current multidisciplinary intervention model that is applicable to stroke survivors specifically within the PHC setting.

c) Community Health Workers

Participants mentioned that CHWs are very important within the PHC system but that they are not fully informed on the services that occupational therapists can offer to stroke survivors. They added that CHWs are not trained on the role that occupational therapy can play and therefore they are unaware of how the occupational therapist can support them.

P4: ...on that point of the Community Health Workers, you know that they are in the community but they are not necessarily informed on what we do and the things that we can help them with that they can do for patients. The real core Occupational Therapy rehab kind of stuff, they are not adequately trained.

P1: ...we are not even included in the training curriculum that the Health Workers do receive.

The **lack of knowledge regarding occupational therapy's advantages amongst the CHWs** correlates directly with the findings from CHWs themselves reported in section 4.4.2. Similarly, an unpublished study (Lowe 2015, pp.62–68) demonstrated that CHWs within the PHC setting have little knowledge regarding physiotherapy. This undoubtedly necessitates actions to inform the CHWs on the role of occupational therapists and other rehabilitation team members. The contribution of **CHWs is an underutilized asset** in the health care management of stroke survivors. CHWs can greatly contribute to rehabilitation services. They can be utilized to their full potential once the current challenges and barriers are addressed.

The potential contribution of the CHWs is a structural factor that needs to be considered when designing an occupational therapy stroke program as such a program can accommodate these challenges in the design thereof.

The **underutilization of CHWs** as assets in the MDT within the PHC setting, as well as CHWs' **lack of knowledge regarding the services** that occupational therapy can offer, are structural factors that need to be considered when designing an occupational therapy stroke program for the PHC setting. These factors can potentially play a vital role to breach the communication gap between the occupational therapist and the stroke survivor and it will have a definite impact on the content of such a program. CHWs further have the potential to greatly contribute to the rendering of rehabilitative services to stroke survivors and their contributions should be considered when designing such a program in future.

d) Summary: Human Resources

The following structural factors relating to human resources were identified as prominent considerations in the design of an occupational therapy stroke program for

the PHC setting: the limited number of allied healthcare professionals and the underutilization of CHWs regarding the roles and services occupational therapy can offer to stroke survivors.

Strengthening human resources for allied health care, especially occupational therapy, and the effective utilization of available human resources are critical factors that need to be considered in the design of an occupational therapy stroke program for the PHC setting.

4.5.3.3. Resources: Non-Human

Themes	Categories	Codes
4.5.3. Structural Factors	4.5.3.3. Resources: Non-Human	a) Finances
		b) Transport

Non-human resources is another major factor that needs to be considered when designing an occupational therapy stroke program as no interventions can be presented without resources. During the focus group, two main codes relating to non-human resources emerged, namely: finances and transport. Each code will henceforth be discussed:

a) Finances

A big concern for the participants was the lack of adequate financial resources in the TMHD. The lack of financial resources is seen as a barrier:

P2: ...we don't get budget for consumables, if say we do groups, so we always want to do activities in a group so we either have to do recycling or generate your own funds. So I think that is something that does not always support from a structural, financial side.

P1: But most of us do have budgets, but the budget is very limited in what you can do with it. It is mostly for assisted devices and yes that is basically it, and there is maybe some stationery.

P3: like we don't have a budget so we have to beg, borrow, steal from the others to get the assistive devices for our patients.

Obviously, occupational therapists in the TMHD are **not adequately supported in terms of financial resources**. This has a negative impact on occupational therapy service delivery to stroke survivors and the lack of funds should be kept in mind when designing an occupational therapy stroke program for PHC. The lack of inclusion of occupational therapy in the relevant policy and legislative documents may further impact on the distribution of financial resources to occupational therapy services (cf. 4.2.2.1.).

Poor financial planning and **inadequate resource allocation** (by the provincial management) are two structural factors related to the non-human resources to render and present such a program.

b) Transport

Another challenge was the unavailability of transport:

P3: transport is a big issue with us; in government there is always a transport problem. Either the car is broken or the car had an accident or it is not starting or there isn't a car or there isn't money for it to go. So a patient that you would have seen once a month is now skipped for another month, so then they don't get the treatment.

P1: Transport is always a problem because we don't have allocated transport which is always available for us, you have to beg, borrow, steal and get in wherever. Also the car is not accessible to transport devices and your equipment and things that is needed.

Not only is **transport not readily available**, but the available transport is also **not suitable to transport equipment and devices** such as wheelchairs to the clinics. This is a major concern as the clinics do not offer any equipment and necessary equipment should be taken along on clinic outreach (cf. 4.3.2.; 4.3.3.). Another major concern is the negative influence on the stroke survivors as they miss out on valuable therapy sessions.

The lack of available and suitable transport needs to be carefully considered in the design of an occupational therapy stroke program for PHC. The program needs to make provision to either overcome or eliminate the challenge of transport. This will prevent a

'no-show' by occupational therapists and it will ensure that a therapist is readily available to present a stroke program within the PHC setting.

c) Summary: Resources Non-human

In summary, the non-human resources are just as important to take into consideration as the human resources when identifying the structural factors that will influence the design of an occupational therapy stroke program for the PHC setting. Financial limitations will have a definite impact on the content of the program as it will limit the availability and amount of consumables and equipment for the program. The lack of transport for occupational therapists from the hospitals to the PHC clinics is another factor that needs to be considered. Provision should be made within the planning and design of such a program to overcome and eliminate transport challenges. An occupational therapy stroke program can only be relevant and feasible if these non-human resource challenges are acknowledged and addressed or accommodated.

4.5.3.4. Systems

Themes	Categories	Codes
4.5.3. Structural Factors	4.5.3.4. Systems	a) Policies
		b) Communication

The last category that emerged regarding the structural factors theme was that of the systems and codes related specifically to the policies regarding occupational therapy (and rehabilitation) within the PHC setting as well as communication with the PHC stakeholders. Each code will be discussed individually.

a) Policies

The document review (cf. 4.2.2.1.) clearly illustrated that relevant healthcare policies do not support the occupational therapist in rendering services within the PHC setting. This lack of support is also perceived by the occupational therapists themselves and this has been a negative influence on the occupational therapists' work:

P1: I think you could go and look at all the policies in the Primary Health Care re-engineering and it states rehab, but it is nowhere to be found. And that is for all the other documents, documentations, National, Provincial, District, it doesn't matter. Rehab is nowhere, in many documents they don't even mention the word rehab, in some it is mentioned but that is it, and even in the District Health Plan which is the health Plan according to which the District must function, we are not even mentioned. So we don't have any platform to stand on to bargain for anything. But it is not even in the Free State Budget Speech, it is not reflected in the Districts, so it stops and it has been like that for years, for many years and I don't see it changing soon.

P1: ...it is also very frustrating, and it is in all the documents, the ones from the Government, the ones from Non-Government Organisations, it is all of them. Rehab is just not there and if we are mentioned it is very little as I said, it is health promotion. It is not therapeutic and I know that occupational therapists are the only contributors to decreasing patients' length of stay in hospital, but they don't see it that way, they don't worry about that. So I think a change have to come from very high up, not from bottom up.

The **exclusion of occupational therapy in policy** influences the occupational therapists' ability to fully provide the services they would like to offer their clients, especially stroke survivors. The exclusion of rehabilitation services, such as occupational therapy, from policy was experienced very negatively. It was noted that therapists are experiencing hopelessness as they feel that they are fighting a system that is not recognising them. Another participant mentioned that, where occupational therapy is included in policy, it is not always possible to execute what the policy states:

P3: The wheelchair issuing policy states that any patient should be issued with a wheelchair if they are in need of one, but that is not always possible due to funds or there are nothing available. So the policy is great but keeping other people to actually look at it and also implement it... the policy is written like, on discharge the patient must get a wheelchair if they are in need of one, but that is not the reality at all.

The **lack of proper support from policy and higher structures** is of great concern for occupational therapists who are working within PHC in the TMHD. This concern has also been highlighted by Dayal (2010, p.25) and Dizon *et al.* (2016, p.6). Not only does the lack of inclusion in relevant policies contributes to negative morale amongst staff, but it also has a definite negative influence on the services that stroke patients receive. The exclusion of the occupational therapist in relevant policies results in poor support from higher governing structures. If this structural factor is not addressed, an

occupational therapy stroke program for PHC will not be feasible as it will not receive support from a human and non-human resource perspective.

b) Communication

Another factor that the participants highlighted as a challenge within the PHC system is that of communication with relevant stakeholders. These stakeholders include the clinic staff as well as the patients:

P3: But another difficult thing that we have is communication with the Clinic itself. There isn't telephones necessarily so if you are going to miss a Clinic visit say you have no transport, you want to move it and spare your patients that drive all that way down to the Clinic you cannot reach them.

P3: And the same with the patients, not all them have numbers or able to be contacted, so it does make it difficult to communicate.

The challenge of **not being able to reach the clinic or the stroke survivor** when a clinic visit cannot be honoured has a negative influence on the therapy process. It may lead to patients arriving at clinics (after spending a lot of money on transport) just to find that no therapist arrived at the clinic. The factor of communication challenges needs to be carefully considered to ensure that it is not a barrier to the feasibility of an occupational therapy stroke program for the PHC setting.

c) Summary: Systems

In summary, two important structural factors relating to systems that need to be considered when designing an occupational therapy stroke rehabilitation program in PHC are policies and communication. The occupational therapist working within the PHC setting should urgently advocate for the inclusion of rehabilitation services, specifically occupational therapy, into PHC re-engineering policies. Without this recognition, no support will be offered to ensure that an occupational therapy stroke program will be feasible.

4.5.4. PROCEDURAL FACTORS

The second theme that emerged during the focus group discussion was that of the procedural factors that need to be considered when designing an occupational therapy stroke program for the PHC setting. This theme was divided into two main categories, namely: occupational therapy interventions and education and support. Each category will be discussed with its respective codes.

4.5.4.1. Occupational therapy intervention

Themes	Categories	Codes
4.5.4. Procedural Factors	4.5.4.1. Occupational therapy intervention	a) Acute Rehabilitation
		b) Group intervention
		c) Home visits
		e) Cultural competency

As described in sections 2.3.1. and 2.3.2., the occupational therapist is equipped to deliver a number of services to stroke survivors such as aspects of intervention and the roles occupational therapists can play in the rendering of services to stroke survivors in the TMHD. The codes for this category are divided into acute rehabilitation, group intervention, home visits, communication, and cultural competency.

a) Acute rehabilitation

All the participants indicated that their first contact with the stroke survivor is in the hospital and that is also where acute occupational therapy assessment and rehabilitation commences:

P4: Usually we pick the patients up while they are still in hospital where they have been admitted after a stroke and with the Physio; the Occupational Therapist goes and assesses the patient to see what is the need. From there we start the whole treatment process.

P4: With the initial assessment in hospital we usually look at first, mobility. Can the patient get out, does he need a wheelchair, are they aware enough even to start moving around with purpose? And then assessment of the affected site, how much movement do they have and are they able to use that hand or foot functionally. So it is all the basic abilities and how it relates to the function that they need to be able to do.

From the verbatim quotes it is evident that the participants assess their stroke survivors while they are still in the hospital:

P2: I don't, use any formal tests for assessment... we usually use just motivation sheets and then you can use, I guess the scale for the muscle tone that we use, so there is certain tools that we use during the assessment. But we don't have any formal assessment tests available.

P3: You know a little bit of background information, what role did they do, what do they still want to do etcetera, and what the family want them to do as well.

Thorough **assessment of the stroke survivor is a crucial aspect** when occupational therapy services are rendered. A proper assessment allows for appropriate goals to be set within therapy. However, the occupational therapists are not using any standardized assessment tools to assess their stroke survivors in the hospital. Although the aim of the discussion was not to identify why standardized assessment is not used, it will be worthwhile to explore the reasons for the non-use of standardized assessments in the future. **Standardized assessments are crucial in providing evidence-based results of the effectiveness of occupational therapy interventions** as well as of the **establishment of outcome measures**. Danzl and Hunter (2013, p.208) proclaim that outcome measures are crucial to ensure that clinical decision-making can be justified and that therapists have 'a leg to stand on' to justify why stroke survivors need certain services as well as why certain equipment is needed. Furthermore, the manner in which the assessment of the stroke survivor is conducted, will definitely influence the impending therapy goals and planning for the stroke survivor as argued by Woodson (2008, p.1021).

Although participants did not use standardised assessment tools, one participant mentioned that they take an individual approach to each stroke survivor by setting goals with the inputs of the stroke survivor:

P1: ...we also ask them what is the most important thing they want to get back. So because it doesn't help you have your goals and it doesn't agree with what the patient wants, so that one is very important to ask the patient and the family, what do they want, which is sometimes very different from what we want.

P2: I also try to use GAS goals.

Participants emphasized that **goals are individualized** and that each stroke survivor is treated differently according to his/her own needs. Since the occupational therapist tends to treat the stroke survivor in a **holistic manner**, the focus does not only fall on the stroke survivor. The participants focused additionally ardently on the family members of stroke survivors. The families are already involved in the treatment of the stroke survivor in hospital and they form part of the discharge planning:

P1: the family integration process actually starts in hospital, in hospital already with education sessions and training them in transfer and mobility and independence.

P4: And on discharge we make sure that the family, we assess the family's knowledge base of what they are supposed to do for the patient and what not.

From the verbatim quotes it is evident that the participants value the role that the occupational therapist plays in educating the families of stroke survivors on discharge from hospital. The role of the family in the therapy process will be discussed in more detail in section 4.5.4.2.

The participants commented that, once a stroke survivor is discharged and is returning to his/her home, they book a follow-up visit for occupational therapy on an out-patient basis at the hospital or at the survivor's local PHC clinic. However, the frequency of follow-up visits at the PHC clinics is limited:

P2: ...if they get discharged we follow up regularly at the Primary Healthcare Clinics and, but this is only once every two weeks, and due to patient loads a lot of times patients are only seen once a month. So the amount of therapy that client receives is quite limited.

P1: ...we work mostly on an outpatient basis versus the Clinics.

P3: So we also start in hospitals if we can, but we also see on an outpatient basis and also visit the Clinics. The further Clinics, we do some in town and then we do also in the further ones on the outreaches of our District. The in town ones we get to see them once a week, but the further ones are only once a month.

As mentioned before, very **little information is available on outcome measures as well as the effectiveness of occupational therapy services** that are rendered to stroke survivors within the PHC setting. The **frequency and timing of occupational therapy sessions** for stroke survivors as well as the lack of the **use of standardized assessments** are some of the aspects that still need to be investigated to ensure that outcomes are measured accurately.

The **frequency and timing of therapy sessions** is, however, not the only factor that influences a change in the condition of the stroke survivor. The **quality of therapy** that stroke survivors receive is also questionable, as described in section 4.3.3. The PHC clinics do not offer adequate space or equipment to render occupational therapy services to stroke survivors. The **lack of research and proof on the effectiveness of rehabilitation services** are also pinpointed by the *Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020* which asserted that a paucity of rehabilitation indicators exists (Department of Health 2015a, p.8).

Providing occupational therapy services to stroke survivors in the PHC setting is a complex and sometimes difficult task. Occupational therapists need to address a wide range of rehabilitation needs of the stroke survivor within a very short period of time and often within severe resource constraints. Despite these challenges, occupational therapists in the TMHD still persist in providing quality service to their stroke survivors.

The **lack of outcome measures** and the accompanying **lack of proof on the effectiveness** of occupational therapy services within PHC, are crucial procedural factors that need to be considered in the design of an occupational therapy stroke program to ensure its relevance and credibility. Furthermore, it is essential to design such a program to **meet the needs of stroke survivors in a holistic manner**, ensuring that such a program is relevant.

b) Group intervention

Some of the participants mentioned that they are using group therapy as a means of providing occupational therapy services to their stroke survivors:

P4: we do the acute rehab with the patient and once they get to the phase where they are a little bit more mobile and independent then we include them with the CVA groups, so that it is not an individual process all the way. And in the groups we continue with the rehab. Some they are in the group now for 5 years, so we continue with support, and that really does help with your staff shortages.

P4: And the patients learn from each other, they give each other ideas on does this work for me or that work for me, so they really do learn from each other.

P3: ...we also do a lot of support groups, which is very fun for the patient as well you know. You create that, not only that informational support but it also gives that emotional support that they need, and also for the fact if you have a granddad that the family members come with, it gives them that support to realize I am not alone in this.

The use of group therapy has been indicated as an effective means of rendering services with a limited number of healthcare staff (Draper, Draper and Bresick. 2014, p.6). Draper, Draper and Bresick (2014, p.6) mentioned that patients with chronic diseases (such as stroke) enjoy group activities and that they are motivated to comply with treatment regimes due to the group responsibility that is generated. Mehdizadeh, Mehraban and Zahediyannasab (2017, p.74) added that group therapy can affect the stroke survivor's performance and satisfaction, while Naidoo, Van Wyk and Joubert (2017, p.9) pronounced a persisting need in PHC for the formation of more occupational therapy support groups for people living with disabilities.

Due to the number of benefits that group therapy can offer the stroke survivor and his/her family as well as the benefits for the occupational therapist to overcome staff shortages, a **group program for stroke survivors within PHC** may provide a possible strategy to overcome challenges such as human resource constraints. As this model is already implemented in some sub-districts in the TMHD, this is a positive procedural factor that can be further researched for future implementation. The presentation of group therapy will, however, largely depend on the success of intersectoral

collaboration as the PHC facilities do not offer the space to present groups within the communities (cf. 4.3.3.).

c) Home visits

None of the participants, at the time of this study, embarked on any home visits to stroke survivors:

P1: ...you cannot do home therapy, home visits and that is also, you cannot, it is inaccessible. It is even worse than going to the Clinic because you don't know what you find in the houses, the patient can be lying on the floor, no chair, no nothing you know. So you cannot also do therapy there and it is also very dangerous.

Participant one mentioned that home visits are too dangerous and that the home setting may not have adequate space to provide occupational therapy services. This may indicate a lack of insight and understanding amongst the occupational therapists in the TMHD on the needs of their clients. In a study effected in the rural Kwa-Zulu Natal province of SA, Naidoo, Van Wyk and Joubert (2017, p.8) found that people living with disabilities pronounced their need for occupational therapists to conduct home visits as this would enable them to better understand the challenges of these people, thus allowing for improved intervention planning.

Although **home visits are seen as a potentially positive procedural factor** in providing occupational therapy services to stroke survivors, this is not a practice amongst occupational therapists employed in the TMHD. This is a factor that should be considered when designing an occupational therapy stroke program for the PHC setting as it may influence the relevance of aspects included in the program. It is recommended that the practice of home visits should be explored in the future to ensure that the program design will also be relevant to the specific challenges that stroke survivors are facing in their homes.

d) Cultural competence

Another important aspect that needs to be considered is the cultural competency of the occupational therapy staff:

P2: Because I think there are cultural things as well that we have to consider, in some cultures it is fine is if my daughter is feeding me and I don't have to do it myself where yes I think we have to also keep that in mind.

P2: ...very important to ask the patient and the family, what do they want, which is sometimes very different from what we want.

P4: I have experienced it that way [that it is a cultural thing] and even if it is a younger patient his mother or her mother will take the carer responsibility and they go back to baby. The patient I can say is babying.

It is evident from the participants' comments that certain cultural aspects need to be taken into consideration when rendering occupational therapy services to stroke survivors. A study comprising occupational therapists who were doing their community service year within rural PHC settings, indicated that the therapists did not feel culturally competent enough as they did not have sufficient insight into *the norms, values and belief systems* of their patients (Naidoo, van Wyk and Waggie 2017, p.41). Grandpierre *et al.* (2018, p.11), furthermore, pointed out that culturally competent healthcare services can be developed by addressing the barriers that prevent cultural competence, including language barriers and poor cultural awareness.

Knowledge of the **cultural norms and values of the community being served**, as well as the **cultural competence of the occupational therapists** and other rehabilitation workers, are important procedural factors that will impact on the design of an occupational therapy stroke program for the PHC setting, ensuring that such a program is relevant.

e) Summary: Interventions

In summary, the occupational therapists who are working in the TMHD make use of a number of intervention strategies to provide stroke survivors with rehabilitation services. Therapy commences with acute rehabilitation in the hospital and is followed up on an out-patient basis either at the hospital or at a PHC clinic. Group therapy was mentioned as a potentially effective strategy to overcome staff shortage challenges. These are two important factors that need to be considered when designing an occupational therapy stroke program for the PHC setting. These factors should, however, always be

considered together with the valuable information that can be gathered from home visits as well as appropriate cultural awareness among occupational therapists. The combination of these factors can contribute to a relevant and feasible occupational therapy stroke program.

4.5.4.2. Education and support

Themes	Categories	Codes
4.5.4. Procedural Factors	4.5.4.2. Education and support	a) Family education
		b) Other roles of the occupational therapist

Another category that emerged under procedural factors was education and support. Apart from direct therapeutic interventions, it was evident that the participants provided a number of other services to the stroke survivors and their families. The category of **education and support** was contained into two codes, namely: family education and other roles of the occupational therapist.

a) Family education

The involvement of the family in occupational therapy sessions was highlighted by the participants:

P2: So the amount of therapy that client receives is quite limited. So I think a lot of our treatment has got to do with family education and family training and a lot with independence with regards to activities of daily living. I think that is our main focus especially if our clients are at an advanced age assisting the family members to make like easier.

P3: The further Clinics, we do some in town and then we do also in the further ones on the outreaches of our District. The in town ones we get to see them once a week, but the further ones are only once a month. So like number 2 said it does really affect the intervention a little bit, so you have to work with the families.

P2: ...we only see them for a little bit, so the family has to buy into that if they want them to reach their goals.

As was mentioned in section 4.5.4.1., **family intervention** and involving the families in the therapeutic process, plays an important role when the occupational therapist is providing services to stroke survivors within the PHC setting. This is mainly attributed to the limited time available for individual therapy and the **role transition to the family** of the stroke survivor. The participants feel that the family plays a vital role in continuing with therapeutic interventions at home in-between occupational therapy sessions at the PHC clinic. This is supported by Cawood and Visagie (2016, pp.25, 26) who indicated that it is important to include carers of stroke survivors in occupational therapy sessions with the aim of training them to assist the stroke survivor at home with mobility and ADLs. For the family to continue with therapeutic interventions at home, **family education is non-negotiable** to ensure that the correct information is taken home as well as ensuring that the family members are competent and skilled in caring for the stroke survivor at home. As portrayed in section 4.4.5., family education regarding the handling of stroke survivors is crucial to avoid abuse and neglect by their families.

The content of the education regarding interventions at home was elaborated on by participant four:

P4: ...start with practical transfer. We tell the patient, this is how you are going to do it and help them to do it, so that they can have their first experience in doing it correctly.

P4: Many patients we find that the family do feel it is their responsibility to do things for the patient, so we have a huge part in playing in educating the family that the guy can actually do it himself. They don't need to do it for him because he had a stroke, he can use his right arm, the left arm is getting better, he can do these things.

P4: So with the hands on therapy that we do that patient is already involved, or the family in doing the therapy for the patient so that, it is a bit of a demonstration but already a practice in the therapy session for the patient.

It is apparent that **role-change** is taking place between the therapist and the families. Families now become the “therapists” of the stroke survivors at home and this is a big responsibility to take on. Nonetheless, given the current realities of the PHC setting in SA, equipping families to take on this therapeutic role seems to be vital to the successful rehabilitation of stroke survivors making use of PHC services in the TMHD.

Family education is a vital and integral part of occupational therapy services that are rendered to stroke survivors. **Family involvement and education** is a major procedural factor that needs to be considered when an occupational therapy stroke rehabilitation program is designed for the PHC setting as it implies the possible inclusion of families into such a program.

b) Other roles of the occupational therapist

The focus group revealed that the participants did not only provide direct occupational therapy intervention and family education, but they also fulfilled other roles:

P3: So a lot of the times we assume that the nursing staff or the doctors gave them information [about the diagnosis] but the parents or the family might not be ready in that time to actually take in that information, so when you start off and you just give it to them again, for the upmost time maybe.

P1: ...working in Primary Health Care many times it is the therapist that breaks the news, that tells the patient what is actually wrong, the doctors and the nursing staff just ignore the topic. So in many cases it is the therapist that must spill the beans...

P2: ...we also play a part in the families' acceptance of the disability, especially for the patient as well. So you have to be devil's advocate if I can say like that to say, okay but remember this is the diagnosis, this is the implication... So we have to play an emotional role as well preparing the patient for acceptance of the disability, if there is a severe disability.

P2: I think most of us work in multi disciplinary with Physiotherapists or the Speech Therapist so as a team there is always one person that is the motivator and the supporter and it is usually the Occupational Therapist.

From the verbatim quotes it is important to take note that, often, no other profession takes up the role of "spilling the beans" and provides the stroke survivor with the **necessary insight into the pathology and the prognosis** of having suffered a stroke. This is a complex process that the occupational therapist takes on as it entails assisting the patient and the family to work through the grieving process. This is an important aspect as it portrays the complex nature of occupational therapy service delivery within PHC amid the challenges of the few therapy sessions that are available to address all the needs of the stroke survivor and his/her family. The occupational therapist

undoubtedly also **fulfils the role of a motivator** as the stroke survivor and his/her family are **assisted to work through the mourning process**.

The additional roles of the occupational therapist within the PHC setting is a procedural factor that needs to be accounted for when designing an occupational therapy stroke program for the PHC setting. It implies that the program will not only consist of direct therapeutic interventions but that the program will include a number of other indirect areas that need to be addressed, such as supporting and motivating patients and family members through the processes of grief and rehabilitation.

c) Summary: Education and support

In summary, the category of education and support demonstrated that the occupational therapist, who works within the PHC setting, is required to fulfil a number of roles. Occupational therapists cannot only focus on the physical impairments of the stroke survivor. Providing therapy is a complex process that involves the family and a big emphasis is placed on the emotional health and wellbeing of both the stroke survivor and his/her family. These procedural factors are crucial to take into account in the design of an occupational therapy stroke program for the PHC setting as it will ensure that the program is relevant to all the needs of the served population.

4.5.5. THE STROKE SURVIVOR AS PRIMARY HEALTH CARE CLIENT

Another prominent theme that rose from the discussions was the PHC client, namely the stroke survivor. It was clear that the participants had a very good understanding of each client and the challenges that he/she experiences on a daily basis. This theme consisted of two categories, namely: client characteristics and challenges. The categories will be discussed individually.

4.5.5.1. Client characteristics

Themes	Categories	Codes
4.5.5. The PHC Client	4.5.5.1. Client characteristics	a) Personal characteristics
		b) Awareness of occupational therapy role

When designing an occupational therapy program specifically for the stroke population, it is vital to understand the context of the client. Within this category, participants voiced their understanding of the stroke survivor within two codes, namely: personal characteristics and understanding of the role of occupational therapy. These codes will henceforth be discussed.

a) Personal characteristics

The participants mentioned that there are a number of personal characteristics that they are considering when they are rendering occupational therapy services to stroke survivors within the PHC setting:

P2: I think sometimes we are rushed for time so our patients reality is, oh I just have to listen, say the right thing, I am being interrogated in this 45 minute session and I just have to say the right thing, and at home I will just continue the way things are, I am just coming here because the family members insist on it and the family is bringing me and they will say so I am stubborn at home and I don't want to do the exercises. A lot of them I believe has a lot of pain and we expect certain things of them, so emotionally they go through a lot and we expect them to just be on-board with therapy from day one and I think they sometimes struggle with the transition to go into patient role, to take up the patient role.

It was pointed out that the **stroke survivor might not be ready from the start to take on the role of a patient**. This aspect links directly with the **grieving process** that was mentioned in section 4.5.4.2. This is an important aspect for the occupational therapist to take note of as it will have an influence on how stroke survivors perceive therapy as well as their active participation in therapy.

It is further very important to provide stroke survivors with the opportunity to talk about what they are feeling and experiencing after suffering the stroke and returning to their home environments. This is challenging for occupational therapists as time is limited

within the PHC setting, but the immense value to the stroke survivor and the family should be kept in mind:

P3: ...the whole thing of the patient trying, we are so pressed for time that we don't actually give them that attention that they need to actually vent or to talk about that. You just assume okay you are here, let us do this. We have to stand and we have to do this, we have to dress so they don't get that time and the families may not necessarily be equipped to address that for them as well. So they do need people to actually listen to them for them just to talk to that as well, so yes I think that's one of the great needs.

From the above discussion, the topic of depression amongst stroke survivors arose:

P1: I think many of them feel so guilty about the roles they lost because of their disability and things that they cannot do and the dependency they have on other people that many of them just keep quiet, and at the end they become so depressed that yes, and sometimes we are the only ones that see it, that see that depression. If you open your eyes and you become aware of it, sometimes we are too busy, and it just goes by and many times it is too late, when the depression is so bad but yes we are in many cases the only person that, that patient can open up to and say, I am not feeling so well. Because of everything that I have lost, because he cannot tell it to his caregivers, he has to be thankful and they have to do what he used to do additionally with caring for him. So yes I think many times we look past it.

From the above verbatim quote, it is evident that the occupational therapist needs to be vigilant and look out for underlying **symptoms of depression**. Depression amongst stroke survivors is not a new phenomenon, but it is known to be neglected. Vermeer *et al.* (2016, pp.6, 7) and Terrill, Schwartz and Belagaje (2018, p.4) indicated that healthcare professionals who are working with stroke survivors should be vigilant for signs and symptoms of depression. Terrill, Schwartz and Belagaje (2018, p.4) also stressed that healthcare professionals often do not assess stroke survivors for depression due to limited time and knowledge on the topic. Depression may influence a stroke survivor's engagement in therapy and meaningful activities (Terrill, Schwartz and Belagaje 2018, p.4) and is, therefore, a major factor that needs to be considered when designing an occupational therapy stroke program for the PHC setting. The occupational therapist, in particular, is excellently positioned to address the emotional needs of the stroke survivor due to the wide scope of training that is offered to the occupational therapist.

Another personal factor that emerged during the focus group is the **loss of income**. Many stroke survivors rely on social grants from South African Social Security Agency (SASSA) if they are South African residents, but if they are not, these people are often found to be living in very dire circumstances:

P4: For many patients of ours they have a loss of income, so many of them ask us for a referral to SASSA, so they can apply for a disability account, and it is something that we do after assessment, just at least refer them and it is really a big issues for them because, and with us especially many of the patients that come do not have South African Identity Documents, so they cannot even apply for a grant, so they live in dire circumstances. They can barely come to rehab, they barely have food on the table, so never mind cutting out salt, there is no food. So it is really, some of their needs more basic than even we realise. So just spending time on the basic, basic stuff is often important.

P3: ...the SASSA Disability Grant, ...is every six months that they have to do it, so that anxiety for them when they come in or they are late for a session they just want to make an excuse, sorry we couldn't come, we didn't have money, the grant is not there. And then having to re-apply for that and keep reapplying for that, it is very stressful for the patients.

The financial burden on the stroke survivor and their families is immense and this needs to be considered when designing a stroke program for the PHC setting. It is important for therapists to be aware of the financial status of their clients in order to ensure that the home program and the education that they are given are relevant and do not require them to do things that are beyond their abilities. **Loss of income** is a procedural factor that needs to be considered when designing an occupational therapy stroke program for the PHC setting as it may include aspects of vocational rehabilitation.

Facts put forward in this section underscores the value of having true insight into the personal factors of the stroke survivor and the immense implications it generates for occupational therapy services within the PHC setting. Assisting the stroke survivor to **take on the patient role**, being vigilant for **signs of depression** and addressing the **loss of income** are crucial but challenging procedural factors to consider ensuring that a relevant occupational therapy stroke program is designed to cater for the stroke survivor.

b) Awareness of the role of occupational therapy

It is, however, not only important to look at personal factors when designing an occupational therapy stroke program for the PHC setting. It is also important to investigate the awareness of the role of occupational therapy amongst stroke survivors as it may influence their participation and buy-in into such a program.

The participants in the focus group mentioned that often the **majority of stroke survivors have very poor awareness of the role of occupational therapy**. Stroke survivors do not have sufficient knowledge regarding the scope of services the occupational therapist can offer and secondly they find it difficult to differentiate between the occupational therapist and other healthcare personnel:

P2: ...patients usually, they just want to either speak or walk, that is their main goal. So as an Occupational Therapist it is quite difficult to, to give them the opportunity to see, okay but do you know that feeding yourself is actually also something that you maybe missed.

P3: I get Doctor, Sister, Physio, everything except the Occupational Therapist.

P1: I think because we work multi disciplinary they just talk about the therapist, so some of them know that you get a therapist that is doing more exercise and a therapist that is doing more talking. But for them it is just a therapist.

One participant, however, voiced that stroke survivors, although they are not fully aware of occupational therapy and the services that can be offered, find it easier to approach the occupational therapist than some of the other members of the multidisciplinary team:

P4: I do find that some of the patients approach the Occupational Therapy more comfortably with certain questions and stuff, they wouldn't ask the Physio necessarily, they would come to you with a broad range of questions. Things that you don't even want to address, but they will ask you.

This section emphasizes the need for the creation of more awareness amongst stroke survivors and their families about the roles of the occupational therapist and the services that can be offered. **Creating awareness** is a procedural factor that will influence the design of an occupational therapy stroke program, as it will assist in

ensuring that stroke survivors and their families actively engage in such a program in future. This also joins the call to create awareness amongst other health care staff, such as the CHWs (cf. 4.4.2.), and policymakers (cf. 4.2.2.1.) to ensure that all stakeholders understand the role that occupational therapy has to play in the management of the stroke survivor as well as to ensure that an occupational therapy stroke program for the PHC setting will receive the necessary support, should it be implemented in the future.

c) Summary: Client characteristics

In summary, **client characteristics** is a non-negotiable factor that needs to be considered when designing an occupational therapy stroke program in the PHC setting. Attention should be given to the emotional, physical and social status of the stroke survivor and awareness should be created amongst stroke survivors regarding the services that the occupational therapist can offer them.

4.5.5.2. Challenges

4.5.5.The PHC Client	4.5.5.2. Challenges	a) Accessing therapy
		b) Family life

As part of the theme of the PHC client, challenges were identified as a category. One could ask why these challenges were not listed as client characteristics, but rather separately. It was decided to place emphasis on the challenges that stroke survivors are experiencing within the PHC setting as multiple factors have an influence on the challenges that stroke survivors are experiencing (i.e. not only their personal characteristics). The challenges were supported by two codes, namely: accessing therapy and family life.

a) Accessing therapy

One of the biggest challenges that stroke survivors experience, according to participants in the focus group, is accessing therapy:

P2: ...they pay R400.00 just to get from the rural settlement to the hospital and back. So for them financially they cannot afford it. So that also limits our treatment then they say, we will just come once a month, because they cannot afford it. So not just from a structural side, from the community I think our patients are being exploited.

P1: And if we give them a wheelchair and they have to come with the taxi for therapy they have to pay for the wheelchair as well. So yes it makes it very difficult for you and for the patient.

P3: So I think sometimes our patients are very isolated and they can feel very lonely, so I think the groups can be very helpful, I just cannot see in our situation the transport is too much of an issue to even try to initiate a group. So it is something that needs to be addresses, I don't have the answer how to...

Difficulties in accessing therapy are mainly due to the **exorbitant transportation costs** that the stroke survivor and their families need to pay in order to get to the hospital or PHC clinic; often aggravated by loss of income (cf. 4.5.5.1. a).

The issue of transportation challenges for the stroke survivor is not new, but since no research has been done on this topic in the TMHD before, the findings from previous studies [(Department of Health 2015a, pp.8, 9), (Naidoo, Van Wyk and Joubert 2017, pp.6, 7), Lowe (2015, p.103)] can now be generalized to the stroke survivor population within the TMHD. It is evident from the data that the participants have an in-depth understanding of the transportation challenges that stroke survivors are facing when they are trying to access occupational therapy services within the PHC setting.

It is, however, important to note that this problem cannot be addressed by the health sector alone. Intersectoral collaboration and discussions with all of the relevant stakeholders are necessary in order to address this challenge. This is a negative factor that will influence stroke survivors' ability to attend therapy and especially to attend an occupational therapy stroke program.

b) Family life

Another big challenge identified by the participants in the focus group was that of the stroke survivors' family life:

P3: I think overall sometimes the community can be also kind of a barrier; sometimes I have also had patients that are locked up in their houses because the other family goes to work. So they stay in the house the whole day, clogged up, cannot go out because it is dangerous for the patients and because the whole family is working.

For some families it can be really **challenging to take care of stroke survivors**. In a rural area in the KwaZulu-Natal province of SA a study found that people living with disabilities were often locked inside their homes. They were often abused and neglected, at times even denied access to food. The authors urged occupational therapists to inform and educate families and the people living with disabilities about disability rights and how to handle such situations appropriately (Naidoo, Van Wyk and Joubert 2017, p.7).

The **challenges that the families are facing** when taking care of the stroke survivor, is a very important factor that needs to be considered when designing an occupational therapy program for the PHC setting. Such a program should include the families of stroke survivors and it should place emphasis on how to handle the stroke survivor. This supports the call in section 4.5.4.2. for families to be included in an occupational therapy stroke program for the PHC setting.

c) Summary: Challenges

In summary, stroke survivors are not only burdened with the physical and emotional challenges arising from the stroke, but they also face a number of social issues within their communities. Stroke survivors face exorbitant transportation costs that often prevent them from accessing occupational therapy services. The cost of transportation is a structural factor that needs to be considered as a priority in an occupational therapy stroke program for the PHC setting.

4.5.6. SUGGESTIONS

The last theme that emerged from the focus group was that of suggestions. Throughout the focus group, the participants voiced their concerns, challenges and needs when rendering services to stroke survivors within the PHC setting. At stages during the focus

group, a very negative mood was perceived. Despite all these challenges and barriers, the participants said that they were still improvising and taking initiative in order to provide in the needs of their stroke survivors. The theme of suggestions is supported by two categories, namely: human resources and non-human resources.

4.5.6.1. Human resources

4.5.6. Suggestions	4.5.6.1. Human Resources	a) Therapy staff
		b) Group therapy and CHWs

One of the categories under the suggestions is, without surprise, human resources. This is understandable due to the human resource shortages that have been discussed earlier (cf. 4.2.2.1., 4.2.2.2., 4.5.3.2.) and will henceforth be discussed in more detail.

a) Therapy staff

Undoubtedly, in a health system that is burdened with a chronic human resource shortage, more occupational therapy staff will make services more accessible. The participants in the focus group (who are all based at hospitals) voiced that it would be of great benefit to have more qualified occupational therapists who are employed within PHC and who are based at the PHC clinics:

P2: I think it would be wonderful if there were qualified, more qualified staff that worked on the Clinic basis.

Increasing the number of human resources specifically for the PHC setting will strengthen the occupational therapy services in the TMHD. A stronger service will allow increased access to rehabilitation services by stroke survivors in terms of more regular access to therapeutic services. The ideal of having more human resources for occupational therapy within PHC is also one of the goals of the *Framework and Strategy for Disability and Rehabilitation services in SA 2015-2020* (Department of Health 2015a, pp.11, 16). Unfortunately, due to the lack of policy inclusion of occupational therapy, realizing the goal of more posts within the PHC sector within the FSDoH may be unattainable (cf. 4.2.2.1.).

b) Group therapy and Community Health Workers

During the focus group, the participants voiced that a group for stroke survivors would be ideal within the community setting as well as involving the CHWs in the groups:

P2:...so being at the Clinic communicating with Community Health Care Workers, have a group at the Clinic which is closer to home, more accessible, have a support group there. Have someone who can translate or be the or it is a Community Health Worker if she can manage the discussion in the Support Group, I think that is the ideal world. If they can have groups in the community but, and then just be supervised by an Occupational Therapist or Physio, and then if there is certain cases that needs more attention than the therapist can address those.P2: I think if we can have better communication with the Community Health workers, there is not communication that I am aware of, not in our institution. Though a couple of years back we were involved with some of their training. ...the Health Care Workers they would come with the patient to treatment and that was wonderful, because then you have your 45 to an hour session and they go home with the patient and they go check up on the patient once or twice a week and it had a very positive effect on the patients that I saw when I, but since then I haven't seen a Community Health Worker ever again. So I think communication with the role players is a big thing that we can, we also can play a part in that but yes it is a 50/50. There is 2 partners in this, so I think just to establish a better relationship between the different partners.

The participants conveyed that there would be **great value in involving the CHWs** in the provisioning of occupational therapy treatment for stroke survivors. Firstly, the participants mentioned the ideal of a group that is supervised by an occupational therapist but presented by a CHW who can communicate to the stroke survivor in his/her language. This correlates with recommendations that have been made in section 4.5.4.1. b.

Secondly, the participants suggested that there should be **improved communication strategies** between the different role players within the PHC setting, especially between the occupational therapists and the CHWs. This correlates with the recommendations that have been made in section 4.4.6. that CHWs should be better informed regarding the services that occupational therapy can offer to stroke survivors, as well as the ways by which the occupational therapist can assist the CHWs in their daily tasks.

The CHWs can play a vital role in the presentation of an occupational therapy stroke program for the PHC setting as the CHWs are working at the homes of the stroke survivors. Group therapy, presented by the CHWs, might offer a solution to address the human resource shortages in relation to high number of stroke survivors in need of occupational therapy services. These are two important factors that need to be explored in the design of an occupational therapy stroke rehabilitation program for the PHC setting

c) Summary: Human resources

In summary, the allocation of adequate human resources for the PHC sector is essential to ensure that stroke survivors receive optimal care. As there is no positive outlook towards having a high number of occupational therapists employed within the PHC sector due to financial constraints within the FSDoH, renewed and innovative ways of thinking are necessary to overcome the barriers whilst still addressing the needs of the stroke survivors. The exploration of a group program, with the involvement of the CHWs, was suggested as a model for the rendering of occupational therapy services in the TMHD.

4.5.6.2. Non-human resources

4.5.6. Suggestions	4.5.6.2. Non-human resources	a) Mobile rehab clinic
		b) Care centres
		c) Resources for occupational therapy

The second category of suggestions relates specifically to non-human resource components. The codes under this category include a mobile rehab unit, the use of care centres as well as resources for occupational therapy. Each code will be discussed according to the suggestions that were given by the participants in the focus group.

a) Mobile rehab clinic

A suggestion offered in the focus group was to consider the use of a mobile rehab unit that can move to where the stroke survivors are:

P1: The other things is what we spoke about numerous times, like there is a Mobile Primary Health Care Clinic if there could be a rehab clinic. Yes that can go into the communities and stop at certain places and you see your patient there, with your neuroplinth and all your equipment inside, that could actually assist the community quite a lot.

The use of a **mobile rehab clinic** is definitely a factor that needs to be considered that might have the potential to bring about change for accessing rehabilitation services. It can assist in addressing a number of challenges, for example the unavailability of equipment at PHC clinics. The possibility of mobile rehab clinics is also a factor that should be kept in mind when designing an occupational therapy stroke rehabilitation program for the PHC setting, although more research is needed to explore the feasibility and effectiveness thereof.

b) Care centres

Due to the challenges that families face when taking care of stroke survivors, it was suggested by the participants that care centres should also be considered for the future:

P1: ...and then also going back to many years past then having adult care centers in the community again, because that can also relieve the family to go back to work and it can also assist us in going to a Care Centre instead of Clinic or wherever and also I think see the adult disabled people there.

The **establishment of care centres** is a long term goal that will need extensive planning and financial support from various stakeholders within the community. This is also an area that calls for further research on its feasibility.

c) Resources for occupational therapy

The last suggestion that was made by the participants is that of increasing resources for occupational therapy within the PHC setting:

P3: I think maybe at an institutional basis we can have a little bit more of the recognition for our role, that somebody actually says, you know what, these people are doing something good, let us try and help them with resources.

P3: It must be included in that a bit more where we get a specific car that is the rehab car and we can go to clinics.

Increasing resources for occupational therapy is one suggestion that is easier attainable within the short term as the provisioning of budget and resources is listed as one of the goals of the *Framework and Strategy for Disability and Rehabilitation services in SA 2015-2020* (Department of Health 2015a, pp.11, 16). According to the researcher, resources in terms of consumables (including assistive devices such as wheelchairs) and the procurement of therapy equipment are easily attainable in the short term. These resources will assist the occupational therapists to provide improved services within the PHC setting.

d) Summary: Non-human resources

In summary, just as human resources are essential in ensuring an effective occupational therapy service within the PHC setting, non-human resources are also required. The participants in the focus group came up with very interesting suggestions; however, these suggestions are still in need of further investigation. Increasing resources for occupational therapy has been identified as a suggestion that can be addressed in the short term and the availability of money will influence the design of an occupational therapy stroke program for the PHC setting.

4.5.7. Conclusion on focus group

The focus group has brought forward valuable information relating to the factors that need to be considered when designing an occupational therapy stroke program for the rural PHC setting. Four main themes emerged that included structural factors, procedural factors, the PHC client, as well as suggestions. These themes provided helpful and constructive information to gain insight into the factors that need to be considered when designing such a program.

4.6. SUMMARY OF FINDINGS

The different sets of data that were presented in this chapter addressed all of the objectives of this study. Firstly, the findings highlighted that there are structural factors that need to be considered when looking at the inclusion of the occupational therapist into relevant policies and public healthcare documentation, including the lack of inclusion of occupational therapy in the majority of documents that relate to stroke survivors and PHC.

Secondly, the findings also identified the structural factors regarding the physical environment that is available to render occupational therapy services within the PHC setting. These factors included the lack of space for individual and group therapy as well as the lack of equipment at the PHC clinics.

Thirdly, the findings identified the procedural factors relating to the understanding of the multidisciplinary team on the roles of the occupational therapist within PHC. One of the biggest factors under this category is the lack of understanding amongst the CHWs of the role that occupational therapy plays in the rehabilitation of the stroke survivor.

Fourthly, the findings identified the procedural factors that need to be considered when rendering occupational therapy services to stroke survivors. These factors include the resourcefulness of occupational therapists themselves as well as the additional roles that the occupational therapist takes on. Unfortunately, these factors also include an array of challenges that are experienced by the occupational therapist. These challenges include a lack of human resources, the lack of resources for assistive devices and transport, exclusion from relevant policies, lack of space to render services at PHC and a lack of the awareness of the role of occupational therapy, to name a few.

Lastly, the findings covered the challenges that stroke survivors themselves are experiencing when accessing occupational therapy services within the PHC setting. These challenges include barriers towards transportation, the physical accessibility of PHC clinics as well as personal factors that include depression.

It is evident that both occupational therapists and stroke survivors are facing challenges within the PHC setting and innovative ways of thinking are needed to overcome these challenges.

4.7. CONCLUSION

This chapter encompasses a presentation of data from four data sets, namely: the document review; structured observations at the PHC clinics; structured interviews with the CHWs; and also the focus group with the permanently employed occupational therapists. For each of the data sets, the demographic information was provided and the findings presented together with discussion in relation to relevant literature. Throughout each set of data, triangulation was executed with relevant literature and/or information obtained from other data sets.

The presentation of the different data sets endeavoured to identify the factors that will influence the design of an occupational therapy stroke program for PHC setting. These factors related specifically to structural and procedural factors as well as the challenges of stroke survivors that need to be considered to ensure that occupational therapy stroke rehabilitation for PHC is relevant and feasible.

Chapter 5 will present the data obtained from the stroke survivors while Chapter 6 will present a summary of the findings as well as a collation of the factors that will influence the design of an occupational therapy stroke program for the PHC setting as identified in this study.

CHAPTER 5: PRESENTATION AND DISCUSSION OF RESULTS AND FINDINGS: CLIENT PERSPECTIVE

5.1. INTRODUCTION

The previous chapter focused on providing the reader with the results and discussion of data sets that related specifically to the public health system as well as the perspectives of the health care workers on occupational therapy services to stroke survivors in the TMHD. It was noted with concern that occupational therapists are experiencing barriers in providing services at PHC facilities in the TMHD. These barriers can be attributed, among others, to the lack of inclusion of occupational therapy in the relevant PHC policies and documentation as well as the structural challenges that are experienced in the PHC clinics.

It was further noted that knowledge amongst the MDTs on the role that the occupational therapist may fulfil in providing healthcare services to stroke survivors within PHC in the TMHD is limited. However, despite the challenges, the occupational therapists in the TMHD are positive about rendering services to stroke survivors and they attempt to meet their needs as far as possible.

Even though the previous chapter has already addressed all of the objectives for this study and provided an overview of the factors that need to be considered when designing an occupational therapy stroke rehabilitation program for PHC, the data is not yet representative of all stakeholders. At the centre of providing healthcare services to stroke survivors, are the stroke survivors themselves. It is of utmost importance to also include the perspectives of stroke survivors and to allow them the opportunity to voice their needs and previous experiences when receiving occupational therapy services within the PHC setting. The stroke survivors may bring new factors to the table that need to be considered and may influence the design of an occupational therapy stroke program for the PHC setting.

This chapter will, therefore, focus on the data that were obtained from the stroke survivors during the semi-structured interviews, of which the methodology was

discussed in chapter 3 (cf. 3.4.6.). This chapter will aim at answering the research question for this study:

What are the factors that will influence the relevance and feasibility in the design of an occupational therapy program for stroke survivors within a rural PHC setting in the TMHD?

The combined results obtained from chapters four and five will provide the researcher with a detailed list of factors that should be considered when designing an occupational therapy stroke program for the PHC setting. The list of factors will represent the voices of various stakeholders, including the stroke survivors, contributing to and ensuring that a relevant and feasible program is designed in the future.

This chapter will briefly describe the participants where after the data obtained during the semi-structured interviews with the stroke survivors will be presented and discussed. The data will be presented according to the themes, categories and codes that have been identified during the data analysis of the semi-structured interviews.

5.1.1. Description of participants

A total of six participants were interviewed of which five were females (age range 40-69 years). Only one male was included as the other identified male participants did not show up for the interviews or declined participating in the study. All of the female participants lived in a rural settlement while the male participant lived on a farm. Running water and electricity was not readily available to all of the participants within their home environment. None of the participants were formally employed at the time of this study. All of the participants met the inclusion criteria and have received occupational therapy services within PHC in the TMHD for six months or longer.

5.1.2. Presentation and interpretation of data

The data from the stroke survivors sought to address three of the objectives for this study, namely: identifying the structural factors regarding the physical environment available to render occupational therapy services to stroke survivors within the PHC

setting, identifying the procedural factors that are essential in ensuring occupational that therapy intervention for stroke survivors is relevant and feasible and also the challenges stroke survivors experience while receiving occupational therapy services.

Creswell's method of data analysis was used (Botma *et al.* 2015, pp.223–225) to analyze and interpret the data (cf. 3.4.6.7.). During the data analysis, five themes were identified together with each theme's categories and codes. The data will be discussed according to the respective categories and codes for each theme by making use of verbatim quotes. Furthermore, the data obtained in this chapter will be triangulated with data that was presented in chapter four as well as relevant literature, as suggested by Botma *et al.* (2015, p.176).

An outline of the themes and categories that were identified can be found in Table 5.1:

Research Question	Themes	Categories	Codes
What are the factors that will influence the relevance and feasibility	5.2. Personal experience post-stroke	5.2.1. Initial contact making with stroke	a) I was diagnosed – but no one explained what a stroke was
		5.2.2. Influence of stroke on personal factors	a) Existential distress
			b) Emotional distress
			c) Physical dysfunction
	5.2.3. Influence of stroke on daily life	a) Loss of roles	
		b) Dependence in Activities of daily living (ADL)	
	5.3. Occupational therapy rehabilitation	5.3.1. Influence of the MDT on occupational therapy rehabilitation	a) Role of the MDT
5.3.2. Content of		a) Exercise	

in the design of an OT program for stroke survivors within a rural PHC setting in the THDH?	and help	occupational therapy rehabilitation intervention	b) Home programs
			c) Family education and support
			d) Assistive devices
		5.3.3. Standards of practice for occupational therapy rehabilitation	a) Time and duration of treatment
	5.4. Access to services	5.4.1. Logistical aspects that influence attendance to therapy	a) The location of therapy services
			b) The impact of transport costs
		5.4.2. Personal aspects that influence attendance to therapy	a) The physical energy to attend
	5.5. Personal Meaning and Agency	5.5.1. Personal capacity	a) The importance of a positive attitude
			b) Making plans
		5.5.2. Agency within the stroke survivor population	a) Being able to help others
5.5.3. The stroke survivor and support groups		a) The possibility of support groups	
		b) Location and access to support groups	

5.2. PERSONAL EXPERIENCE POST-STROKE

The first theme that emerged during the semi-structured interviews was that of the personal experiences of the stroke survivors after they had suffered the stroke. This theme emerged strongly in all of the interviews. The feeling amongst the participants was unambiguous that there are a number of issues that they had experienced and had to deal with after suffering the stroke. This theme addresses two of the objectives of this research study, namely the procedural factors that are essential in ensuring

occupational therapy intervention for stroke survivors are relevant and feasible as well as the challenges stroke survivors experienced while receiving occupational therapy services within a PHC setting. This theme has been divided into three categories, namely: initial contact making with stroke, the influence of stroke on personal factors as well as the influence of stroke on daily life. The individual categories will henceforth be discussed.

5.2.1. Initial contact making with stroke

Themes	Categories	Codes
5.2. Personal experience post-stroke	5.2.1. Initial contact making with stroke	a) I was diagnosed – but no one explained what a stroke was

The first category within the theme of personal experience post-stroke is that of the initial encounter with a stroke. This category has only one code, namely: ‘I was diagnosed, but no one explained to me what a stroke was.’ This section will focus on the experiences of the stroke survivors after having the stroke and mostly while they were still in hospital.

a. I was diagnosed - but no one explained what a stroke was

The first category that was identified under the theme of personal experience post-stroke was that the stroke survivors had been diagnosed with a stroke, but that no one explained to them what a stroke was. This category was present in all the interviews and the responses received from the participants were unanimous:

P1: *...she said to me you have this thing called stroke, I didn't even know what kind of a disease it is.*

P2: *[Researcher: ...did the doctor explain to you what a stroke is?] No.*

P4: *The doctor just said to me I have a stroke, I must go to Bethlehem and go to Physio.*

P5: *They didn't explain to me what it was, they explained to me what caused it.*

P6: *[Researcher: ... did they explain to you at the hospital what a stroke is?] No, they did not.*

P7: [Researcher: ...did they explain to you at the hospital what a stroke is?] No, they did not.

Stroke survivors were told that they had suffered a stroke, but that they were not informed what a stroke was. This correlates directly with data that was obtained from the occupational therapists in the focus group (cf. 4.5.4.2. b) who asserted that it is often the occupational therapist who have to "spill the beans" on the pathology and prognosis indicating that the topic is often ignored by nurses and doctors in the TMHD.

The researcher has experienced that it can be devastating for the stroke survivor and his/her family to hear the news of the pathology and prognosis and how this new diagnosis will influence their lives. Hearing the bad news that there might not be a full recovery, may lead to depression as well as difficulties in family dynamics. It may further negatively influence stroke survivors' rehabilitation processes as they may not be motivated to participate in therapy programs due to depression. The topic of depression amongst stroke survivors was also discussed in the results of the focus group with the occupational therapists (cf. 4.5.5.1. a) and will be further elaborated on in another category, namely emotional distress (cf. 5.2.3.).

Occupational therapists should be vigilant to observe and inquire whether stroke survivors and their families have been supplied with comprehensive information regarding the diagnosis. The occupational therapists' role in the **sharing of information on the pathology and prognosis** of stroke as well as the **possibility of accompanying depression**, are procedural factors that will influence the design of an occupational therapy stroke program.

5.2.2. Influence of stroke on personal factors

Themes	Categories	Codes
5.2. Personal experience post-stroke	5.2.2. Influence of stroke on personal factors	a) Existential distress
		b) Emotional distress
		c) Physical dysfunction

The second category that emerged under this theme was the influence of stroke on personal factors. The personal factors influenced by the stroke are supported by the

codes of existential distress, emotional distress and physical dysfunction. Each of the codes representing personal factors will be discussed individually.

a. Existential distress

Existential distress was a code that emerged during the interviews and often emerged as participants voiced questions like: “Why me?”:

P2: *I could not understand things. I don't understand why me.*

For participant two (in particular) it was very difficult to deal with all the changes brought about by the stroke. After the stroke, she could not come to grips with her situation and she could not understand why she was a victim of a stroke. After suffering a stroke, the stroke survivor might not be ready to take up the patient role as yet. This was also noted during the focus group where the occupational therapists indicated that stroke survivors are not immediately ready to start with rehabilitation as they have to work through emotional issues first (cf. 4.5.5.1. a).

The emotional distress that accompanies a stroke is a common phenomenon amongst stroke survivors. In a study that conducted to determine the factors that influence post-stroke psychiatric distress, Mccurley and colleagues found that emotional distress already surfaces during the acute phases of stroke and continues into the chronic stages of the recovery process. They further highlighted the importance of attending to the emotional distress experienced by stroke survivors and their families early in the recovery process as it may influence the physical recovery and morbidity and mortality risks for both the stroke survivors and their families (Mccurley *et al.* 2018, p.2).

The **existential distress** and the accompanying **depression** that stroke survivors may experience are two impacting factors that need to be considered when designing an occupational therapy stroke program for stroke survivors in a PHC setting.

b. Emotional distress

During the interviews with the stroke survivors, the code of emotional distress emerged a number of times. It was clear from the interviews that stroke survivors are burdened with a number of challenges, including their emotional state:

P1: I felt some pain cause even when I was looked after they used to have to assist me with everything. She (the therapist) helped cause she helped a lot emotionally. They explained to me that it (affected hand) wouldn't go back to its normal.

P1: If a person is not able to walk at all. Or when a person isn't even motivated enough. And they are forever crying. Saying ahh...feeling sorry for themselves. That's the thing that makes people reluctant to come (to therapy). The thing that is important is that they need to get emotional help. That is probably the most important. We are able to help them when they are emotionally okay. Then they will do other things afterwards.

P2: I was afraid of people. I was not well emotionally, I used to cry. I could not understand things.

Dealing with one's emotions after a stroke can be challenging, as stroke survivors have to make a number of adaptations. Not only do they have to face physical limitations and adaptations, but they also have to come to terms with being dependent on other people. Furthermore, they also have to overcome their own internal battle of emotional distress. Mccurley *et al.* (2018, p.4) found that stroke survivors experience feelings of guilt, sadness, hopelessness and helplessness. This topic also emerged in data from the focus group with the occupational therapists. The participants voiced that stroke survivors go through a lot emotionally and that often therapists miss the fact that they are not yet ready to take up the patient role (cf. 4.5.5.1. a). More than a decade ago, Thomas and Lincoln (2008, pp.1243, 1244) already pointed out that stroke survivors experience emotional distress. They also raised the important factor that the emotional distress often persists for more than six months after the stroke and advised that the emotional status of stroke survivors should be monitored and attended to within rehabilitation programs, even during the chronic phase. Mccurley *et al.* (2018, p.2) indicated that often interventions for depression symptoms are only executed when these symptoms are already chronic. Terrill, Schwartz and Belagaje (2018, p.4) further

added that healthcare professions often do not assess their stroke survivors for depression due to limited time and scanty knowledge of the topic.

As stated in the interviews, it is important that occupational therapy also addresses the emotional component and not only focus on the physical aspects of the stroke survivor. Terrill, Schwartz and Belagaje (2018, p.4) argued that depression may influence a stroke survivor's engagement in therapy and meaningful activities, while Mccurley *et al.* (2018, p.3) added that the uncertainty that stroke survivors experience post-stroke regarding their recovery, should be addressed timeously.

Not only does a stroke cause emotional distress for the stroke survivor, but it also influences the family. Wan-fei *et al.* (2017, pp.4929, 4930) and Mccurley *et al.* (2018, pp.1, 2) indicated in recent studies that both stroke survivors and their families are at risk of experiencing anxiety and depression. Wan-fei *et al.* (2017, pp.4929, 4930) found that depression of the family members may lead to a negative impact on the physical health of the stroke survivor, while Mccurley *et al.* (2018, p.4) added that families are unsure how they will be able to manage their family and work life and still take care of the stroke survivor. Thus, the emotional aspects of both parties should be addressed during the rehabilitation process.

Occupational therapists should, therefore, be vigilant and look out for underlying symptoms of depression amongst their stroke survivors and their families. **Emotional distress (for both the stroke survivor and the family)** is a procedural factor that needs to be considered when designing an occupational therapy stroke program for stroke survivors. Not only will the emotional distress influence the procedural factors in designing such a program, but it will also have an influence on the content of and adherence to such a program.

c. Physical dysfunction

The pathology of stroke includes a number of physical disabilities (cf. 2.4.1.) and the severity of these disabilities differs amongst stroke survivors. Participants voiced their experiences regarding their own physical dysfunction:

P1: That I don't see myself being able to walk without the crutch after those exercises.

P2: People can hear that I am coming. And this leg sometimes gets wobbly. When I walk.

P4: I was not able to walk, I was not able to do anything.

P5: After the stroke. This hand was not there at all. It was just straight all the time. There was nothing. Now I have come to therapy. This hand is now there. It can be straight, it can be used. I can lift the hand up. The only problem now is that it just won't hold things.

P6: Although a walk is a challenge, when I walk during long distances I get tired easily. I appreciate that I am not confined to a wheelchair. Cause it's difficult cause when I have fallen in the house and I would need to rely on the child to help me get up and things like that. Also to use my left hand. I have to write left in my left. But not as I used to before. I am not able to bathe.

P7: Before, I couldn't do anything.

From the verbatim quotes, it is evident that the participants all have different physical dysfunctions that limit their participation in their ADL. These physical dysfunctions range from difficulties to walk to difficulties in using the affected hand and arm. As the severity of physical disabilities differed amongst participants, so will their experiences of the dysfunction and the effect that it has on their lives be different. This is also supported by Gillen (2013, p.846).

It is important to note that the list of physical limitations related by the participants in this study doesn't constitute an exclusive list of dysfunctions - there are many other physical dysfunctions as each stroke survivors presents differently due to different brain areas that are affected with the stroke (Woodson 2008, pp.1009, 1010). What should, however, be taken into consideration is the role that the occupational therapist has in assisting with the rehabilitation process to regain functional components or to make adaptations to compensate for the loss of function.

Physical dysfunction (and the diversity thereof) that stroke survivors are experiencing is a procedural factor that will influence the design of an occupational therapy stroke program for PHC. It will, furthermore, influence the structural factors of such a program, as the location of rehabilitation and access thereto need to accommodate these

disabilities. The physical disabilities will also influence the content that needs to be included in a proposed occupational therapy stroke program.

5.2.3. Influence of stroke on daily life

Themes	Categories	Codes
5.2. Personal experience post-stroke	5.2.3. Influence of stroke on daily life	a) Loss of roles
		b) Dependence in ADLs

The last category that emerged within the theme of personal experience post-stroke was that of the influence of the stroke on daily life. This category is supported by two codes, namely loss of roles and dependence in ADL.

a. Loss of roles

A stroke brings about a tremendous change in the life of a person, including a loss of major life roles, as it can be noted from the participants:

P5: *I was able to drive my own tractor when I wanted to plough and plant on my fields. I was able to milk my own cows when I needed to. I was able to drive a manual car. I was able to drive my car.*

P5: *I used to be a soccer coach. - And I am not able to anymore. On Sundays when there were soccer matches I would be the referee. I am not able to do that anymore. It's quite painful because it's something I really loved to do.*

P6: *The stroke changes a person's life. It drastically changed my life. I am a person who likes to be independent and do things for themselves. I had a stroke when my child was 2 years old. It was difficult for me to raise him.*

P6: *It is also difficult to get a job.*

The loss of roles has a negative impact on stroke survivors. As mentioned before, stroke survivors are not able to do things for themselves as they have done before and they are now dependent on family members to assist them to do certain tasks to a certain extent; if not fully dependent. Fulfilling daily life roles such as working, taking care of a child or participating in recreational activities have also become either impossible or challenging. Some stroke survivors had to give up certain roles while

others had to make adjustments, but not always very successfully. Mccurley *et al.* (2018, p.4) claimed that stroke survivors experienced emotional distress due to their role changes and the accompanying changes to their identity. In this study, stroke survivors expressed that they had to transition from being the carer to being the person who is in need of caring. Not only does this cause sadness and frustration amongst the stroke survivors, but it also leads to feelings of guilt and being a burden on their families (Mccurley *et al.* 2018, p.4).

Stroke survivors do not only have to deal with the role and identity changes, but they also have to deal with the effect of their disability on their families. Participant six mentioned an aspect that is often overlooked - the rejection of a life partner.

P6: *Because after that then (the stroke) their father left him.*

Not only did she had to deal with the rejection and the accompanying emotional distress, but she was also left with the physical and financial burden to take care of a two-year-old child by herself, while she was not physically able to do so at that time. Ultimately this has not only affected her, but it also has an impact on her child as she is struggling to find a job to enable her to take care of him. The loss of income for stroke survivors have also been acknowledged by the occupational therapists in the focus group (cf. 4.5.5.1. a). In addition, participants also emphasized the loss of roles, particularly the rejection of a life partner that had a detrimental effect not only on their income but on their lives as a whole.

The **loss of roles** and the accompanying **emotional and financial burden** that it causes are procedural factors that will influence the design of an occupational therapy stroke rehabilitation program. It will influence the content of such a program to ensure that these aspects are addressed within the program. These factors will furthermore influence the procedural factors of such a program as it will determine specific rehabilitation interventions and education activities to address the loss of roles that stroke survivors are experiencing.

b. Dependence in activities of daily living

While stroke survivors are facing physical dysfunctions and role losses, it is inevitable that they would also have difficulties in participating in their ADL. After the stroke, the stroke survivors were dependent on family members to help them to participate in their ADL:

P1: I felt some pain cause even when I was looked after they used to have to assist me with everything. I couldn't do anything for myself. They would take me off the bed. And I would ask them to let me lean on the wall. What they would do is they would just help me to ring the bath cloth and put some soap. And then I would be able to bathe myself (with my non-affected hand). And they would rinse it (bath cloth) and I would continue bathing. Something that I am struggling with even now. I just can't cut things. Ironing is a problem my haemorrhagic side gets tired. I just can't cook pap. Because when I need to stir the pot. And chopping vegetables is very difficult. I need somebody to help me.

P4: It changed...the things that I want to do for myself I can't do anymore. I can't do my washing. I can cook. I can't peel things that I can't cook. I have got my sister who helps me.

P6: I am not able to bathe.

Participating in ADL (and instrumental ADL) is a challenge for stroke survivors. The physical limitations, emotional distress and loss of roles (e.g. a life partner) are influencing their ability to participate in their ADL. In this study, the participants particularly emphasized self-care and home management as problematic areas with which they experienced difficulty.

Naidoo, Van Wyk and Joubert (2017, p.8, 9) argue that people with disabilities (living in rural areas) are in definite need of more occupational therapy services that are adequate and appropriate in addressing their needs, especially with regards to their ADL. From the verbatim quotes it is evident that these stroke survivors are still in need of therapeutic interventions with regards to their ADL. Although some of the participants have regained the ability to participate in some of their ADLs, it is noted that some of them still experience challenges and are still dependent on their family members.

The **dependence and the need for adaptations in ADL** will influence the relevance in the design of an occupational therapy stroke program for the PHC setting. The **need for**

adaptations and independence within ADL as well as **educating the families** on how to assist the stroke survivors in achieving this independence, are procedural and content factors that will influence the design of an occupational therapy stroke rehabilitation program as it advocates for the involvement of family members in such a program as well as for specific content (education and demonstration on adaptations in ADL) to be included in such a program.

5.2.4. Conclusion

In conclusion, the stroke survivors in this study had a number of personal experiences post-stroke that have not only influenced their participation in their daily lives, but also influenced their participation in occupational therapy. These experiences include: not being given an explanation of what a stroke is, participants raising the question: "why me?", emotional distress, physical dysfunction, the loss of roles as well as dependence in ADL. These experiences comprise structural, procedural and content factors that need to be considered when rendering occupational therapy services to stroke survivors within a PHC setting. These factors will influence the design of an occupational therapy stroke rehabilitation program and have been identified as addressing the existential and emotional distress that stroke survivors are experiencing, addressing the physical dysfunction and limitations to ADL as well as addressing the loss of roles. The important role that occupational therapy has to play in the personal experience of stroke survivors has also been highlighted as the occupational therapist should assist the stroke survivors to work through these experiences. Undoubtedly, the aforementioned factors need to be considered when designing an occupational therapy stroke program for a PHC setting.

5.3 OCCUPATIONAL THERAPY REHABILITATION AND HELP

The second theme that emerged is that of occupational therapy rehabilitation and help. Dealing with this theme a number of categories were identified that included: the influence of the MDT on occupational therapy rehabilitation, the content of occupational therapy rehabilitation intervention and the standards of practice for occupational therapy rehabilitation. This theme specifically addresses the objective of identifying the

procedural and content factors (from a stroke survivor's perspective) that are essential in ensuring occupational therapy intervention for stroke survivors is relevant and feasible in a PHC setting. Each category within this theme will henceforth be discussed.

5.3.1. Influence of the multidisciplinary team on occupational therapy rehabilitation

Themes	Categories	Codes
5.3. Occupational therapy rehabilitation and help	5.3.1. Influence of the MDT on occupational therapy rehabilitation	a) Role of the MDT

The first category that emerged under the theme of occupational therapy rehabilitation and help is that of the influence of the MDT on occupational therapy rehabilitation. This category has one code, namely the role of the MDT.

a. Role of the multidisciplinary team

During the interviews, it became clear that there was no standard of practice for members of the multidisciplinary team that was involved with stroke survivors. Participants were asked which healthcare providers they encountered when receiving therapy at PHC clinics:

P2: *...the pastor came and gave me counselling.*

P4: *After the stroke I used to just come here to the clinic. Yah, the last doctor I saw is when I went to the doctor when I first got a stroke. I met the nurse (at the clinic).*

P5: *Yes, I meet the doctor. [Researcher: The nurse?] Yes, them too.*

P7: *No I don't meet the sister.*

Different participants have different experiences regarding the management of their health conditions at the clinics. For some participants, a doctor and nurse are available at the PHC clinic while it is not the case for others. The participants also did not mention any other healthcare personnel, and when questioned whether they are attended to by

a physiotherapist or other rehabilitation team members, the majority of the participants answered in the negative. From the interviews alone it is difficult to draw a conclusion on the reasons why not all members of the MDT are involved in the management of the stroke survivor. From the focus group with the occupational therapists as well as from literature it was, however, noted that the MDT is not always readily available due to staff shortages (cf. 2.2.2.; 4.5.3.2.) which provides a possible explanation for participants' experiences at the PHC Clinics.

The challenge of staffing norms is not unique to the TMHD or the Free State province. This was also a problem found in the Western Cape of SA. Mlenzana and Frantz (2017, p.251) stated that a multi-professional team is crucial in ensuring that rehabilitation is effectively applied within the PHC context. Unfortunately, they found that the majority of the rehabilitation centers in the Western Cape lacked an adequate number of allied healthcare workers (Mlenzana and Frantz 2017, p.251).

Although the composition and use of the medical MDT in PHC in the TMHD are still unclear and in need of further research, it was highlighted by participant two that other role players can also be beneficial to the stroke survivor. Other role players can include a pastor to address aspects of spirituality. This indicates that intersectoral collaboration should be further explored for its feasibility in future interventions (cf. 4.4.4., 4.5.4.1.). The utilization of a full medical MDT, as well as the inclusion of other stakeholders (intersectoral), are keys in ensuring that stroke survivors are addressed in a holistic manner.

For successful occupational therapy intervention, and in specific for an occupational therapy program for the PHC setting to be relevant and feasible, the use of a proper MDT is non-negotiable. Each member of the MDT has a role to play in ensuring the health and wellness of stroke survivors. **Intersectoral collaboration** and **involvement of the MDT** are two important factors that will influence the design of an occupational therapy stroke program to ensure that such a program will be relevant and feasible. This will have an influence on the procedural and content factors of such a program.

5.3.2. Content of occupational therapy rehabilitation intervention

Themes	Categories	Codes
5.3. Occupational therapy rehabilitation and help	5.3.2. Content of occupational therapy rehabilitation intervention	a) Exercise
		b) Home programs
		c) Family education and support
		d) Assistive devices

The second category that emerged under the theme of occupational therapy rehabilitation and help was that of the content of occupational therapy rehabilitation intervention. This category is supported by four codes, namely: exercise, home programs, family education and support and assistive devices. Each code will be discussed individually.

a. Exercise

The occupational therapist is equipped to deliver a number of services to stroke survivors and the presence of the occupational therapist within the PHC setting is perceived as valuable (cf. 2.3.1., 2.4.2. and 4.5.4.1.). The role of exercise and the role that the occupational therapist plays in this regard was a code that emerged strongly in the interviews. Most of the participants mentioned that they have received exercises as part of their occupational therapy treatment:

P2: *...they (therapists) showed us how to exercise, they spoke to us. They taught me how to look after myself. They taught me how to eat properly. They helped me dress and remember things.*

P4: *These exercises that I found there were very helpful. I was not able to walk, I was not able to do anything but when I came to these services I saw myself being able to stand. ...the things that they told me to do and that I did, they were very beneficial to me. And the different exercises that they told me to do and I kept doing. Now I am able to bathe. Now I am able to dress myself. I was helped by these exercises that I do.*

P5: *We do exercises. I have seen much improvement when I compare to the situation I was in initially. After the stroke. This hand was not there at all. It was just straight all the time. There was nothing. Now I have come to therapy. This hand is now there. It can be straight, it can be used. I can lift the hand up. The only problem now is that it just won't hold things....*

P6: And then Mary encouraged me to come to exercises as well.*

*pseudonym

For most of the participants the exercises they received were beneficial and they were able to notice a difference in either their physical function, participation in ADL or both. They perceived the exercises to have a positive impact on their lives. Mehdizadeh, Mehraban and Zahediyanasab (2017, p.74) indicated that mobility activities can positively affect the performance of stroke survivors.

The occupational therapists in the focus group explained that they are giving home exercises to stroke survivors and that these exercises are revised on each visit to ensure progress within the therapy process (cf. 4.5.4.1. a). However, it is suggested that more research should be done on the exact type of exercises stroke survivors received. Further research will not only contribute valuable information towards specific content aspects that need to be included in an occupational therapy stroke program in the future, but it will also contribute towards the development of the standards of practice for occupational therapy services to stroke survivors.

The inclusion of **exercises as an occupational therapy intervention strategy** is a procedural factor that will influence the design of an occupational therapy stroke program for the PHC setting. This factor is also a structural factor as it will have an influence on the space that is needed to execute such exercises.

b. Home programs

The stroke survivors mentioned that they do not only receive exercises during their occupational therapy sessions, but they also receive home programs for exercises at home:

P1: ...would explain to me how to exercise. Then I would to do them at home.

P4: ...what I did is when I got home with a piece of paper that I had (received from the therapist) I showed them (my family) these are the exercises that I must do and which they were able to help me.

P5: *They give me things to do at home with instructions of what how I should do and how I should live. Some of the exercises I do here they instruct me that when I get home, I should do them the same way that I did them when I was here.*

P7: *They gave me a piece of paper to show me how I must do things, what I must do.*

Participants received home programs that included exercises and guidance to cope with obstacles at home. This correlates with comments from the focus group who mentioned that they rely heavily on home programs since they do not see the stroke survivors regularly (cf. 4.5.4.2. a). From comments in the interviews with the stroke survivors as well as those in the focus group, the content and effectiveness of these home programs remain unclear and further research on this topic is needed.

The lack of knowledge regarding the content and effectiveness of home programs refers back to the lack of standards of practice as well as the lack of proper evaluation and monitoring (cf. 2.2.4.) of occupational therapy services within PHC.

Despite the lack of evidence on the effectiveness of home programs, it has been valued as an integral part of occupational therapy rehabilitation services in the TMHD to stroke survivors. The **use of home programs** seems to be a procedural and content factor that will positively influence the design of an occupational therapy stroke rehabilitation program as such a program can be complemented with home exercises and advice, leading to the carry-over of information to home. However, since the effectiveness of these programs is not yet well established, further research should be done to determine the standards of practice for occupational therapy home programs and the effectiveness thereof. Further research on these topics will assist in ensuring a relevant occupational therapy stroke program for the PHC setting is designed.

c. Family education and support

As mentioned in the previous category, the family is involved in assisting the stroke survivors to do their exercises at home. Another category emerged regarding the families of stroke survivors, namely the involvement of the family in occupational therapy sessions:

P1: *It is extremely important (to involve the family). They are then explained to that when you have someone who is ill how do you handle them at home. It's a problem that a lot of us have. It's a thing that could help a lot of people. Because they are the ones who put pressure on a person who is ill. Because sometimes they even say to you when you attempt to do something, ah don't do that you are not be able to don't do that. Scold you, so it is important that they are involved. That they are trained. This person is not doing this on purpose, this is actually what's going on, this person is like this or that.*

P2: *My husband and my children. They bring me (to therapy). They bought a bicycle even. This bicycle is right next to my bed, when I get out of bed they say, "here, get on". They (the therapists at the hospital) used to speak with them. They said to them they must be patient and must persevere.*

P4: *When they saw I was better and walking they stopped coming with me (to therapy). When I was still very very sick they came with me. They were very helpful to help with things that I wasn't able to do.*

P5: *Yes, they (my family) were helpful. They would bring me here. At home if I had exercises I was not able to do they'd help me.*

P7: *They (therapists) showed them (family) what they should do with my hand.*

A few aspects arose regarding family education and support in the interviews. Firstly, it was noted that the families of stroke survivors should be educated and informed on what can be expected of a stroke survivor and what not (cf. 4.5.4.2. a). Participant one commented that families should not be putting excessive pressure on the stroke survivor, but that the families also should not do everything for the survivor. There is a fine line between where families should support and encourage the stroke survivor to do things and where families should assist in ADL.

Secondly, the morale and motivational support that the family can offer the stroke survivor can be of immense value. Families can support the stroke survivors, not only to assist them in attending therapy sessions, but also motivating them at home to do their exercises and to follow their home programs.

It is, however, important to also take note that not all of the participants have experienced such support from their families. One participant mentioned that her family lives in another country and that they were unable to support her:

P6: *I can't say because my family are in Lesotho.*

Since some stroke survivors may experience a lack of family support and assistance, the need to have access to support from someone/somewhere else should not be overlooked. The occupational therapist may assist to arrange such support for the stroke survivor and it is a factor that can be considered in the design of an occupational therapy stroke rehabilitation program for the PHC setting.

Thirdly, it was noted that the role that occupational therapists have to play in educating and supporting the families, is perceived as valuable. Therapists have to teach the families what they have to do at home and how they should be doing it. This correlates with information that was given by the occupational therapists in the focus group where they indicated that families are already involved in the discharge planning of the stroke survivors while they are still in hospital (cf. 4.5.4.1. a). Mccurley *et al.* (2018, p.7) also indicated that the caregiving responsibilities (provided by the medical staff during hospitalization) should be transferred to the family members once the stroke survivors are discharged from the hospital.

However, it is important to note that one participant mentioned that her family was not educated by the therapists - this participant preferred that once she was taught she would transfer the information to her family:

P4: [Researcher: ...*did the therapists teach the family?*] *No they didn't. I am not sure if they will be able to understand the same way I was able to understand. Because I have the problem that's why it is easier for me to understand what is taught.*

This participant was of the opinion that her relatives would not be able to understand as well as she did since they are not the people with the problem. This underscores the importance of assessing each stroke survivor and his/her family thoroughly to determine the family dynamics. Understanding the family dynamics will enable the therapist to provide appropriate education and insight regarding the pathology, as well as making the therapy process appropriate to the circumstances of each stroke survivor.

The interviews with the stroke survivors as well as the focus group (cf. 4.5.4.2. a), make it clear that the family plays a vital role in the continuance of therapeutic interventions at home in-between occupational therapy sessions. Therefore, thorough family education is vital to a stroke rehabilitation program. It is crucial to ensure that the correct information is conveyed to support systems, as well as ensuring that the family members are competent and skilled in caring for the stroke survivor at home.

As mentioned in section 5.2.3., it is also very important to look out for signs of depression amongst the family members of stroke survivors. Depression can have a negative impact on the physical health of the stroke survivor and, therefore, it is recommended that the emotional aspects of both parties should be addressed during the rehabilitation process.

Involving the families of stroke survivors in therapy sessions, **motivating them to assist and support the stroke survivor** and **educating them** on what they can do at home, are central aspects of the occupational therapy services in the TMHD. These are three important factors that will influence the design of an occupational therapy stroke program for the PHC setting as they are procedural and content factors that will influence the composition and content of such a program.

This section advances the fact that adequate family support and training may lead to better health outcomes for the stroke survivors and therefore its value for an occupational therapy stroke program should not be overlooked.

d. Assistive devices

The last code that was identified under the theme for occupational therapy rehabilitation and help was that of assistive devices:

P1: ...they made me a splint. That I don't see myself being able to walk without the crutch...

P4: No, I didn't have a wheelchair. I would just sit at home unable to walk.

Some of the participants were supplied with assistive devices. It is, however, noted with concern that participant four did not receive a wheelchair after her stroke. She was,

therefore, initially confined to her home. Luckily, she made progress enabling her to walk with a crutch, but it raises concern about the level of independence that is offered to other stroke survivors in the TMHD who cannot walk and who are not issued with appropriate assistive devices.

This correlates with the information supplied by the occupational therapists in the focus group (cf. 4.5.3.3. a, 4.2.2.2.), as well as information from the NDoH that indicated that inadequate provisioning of assistive devices are experienced amongst rehabilitation staff (Department of Health 2015a, p.8). Naidoo, Van Wyk and Joubert (2017, p.8) also refer to people living with disabilities (in a rural community in the KwaZulu-Natal province of SA) who are in need of more appropriate wheelchairs that are fit for the rural setting.

The **availability and the necessity of appropriate assistive devices** is an impacting procedural factor for the provisioning of occupational therapy services within the PHC setting, as it will influence how an occupational therapy stroke program is compiled and what specific occupational therapy interventions need to be included in such a program. The **availability** (and ultimately the unavailability thereof) **of assistive devices** will further have an influence on the structural factors and the ability of the stroke survivor to attend such a program, especially the availability of wheelchairs to non-ambulatory stroke survivors. These factors will undoubtedly influence the feasibility and design of an occupational therapy stroke program for the PHC setting.

e. Conclusion

This category, namely **the content of occupational therapy rehabilitation intervention**, has brought forward valuable insights that will influence the design of an occupational therapy stroke program for the PHC setting. The important role that exercises and home programs play in the provisioning of occupational therapy rehabilitation to stroke survivors was highlighted by the stroke survivors. Involving the families in therapy sessions and equipping them with the necessary support and education were deemed important and useful by most of the stroke survivors. Lastly, the effect of assistive devices on such a program was noted and the need for appropriate

devices was highlighted. These are structural, procedural and content factors that will have an influence on the design of an occupational therapy stroke program for the PHC setting.

5.3.3. Standards of practice for occupational therapy rehabilitation

Themes	Categories	Codes
5.3. Occupational therapy rehabilitation and help	5.3.3. Standards of practice for occupational therapy rehabilitation	a) Time and duration of treatment

The third category that emerged under the theme of occupational therapy rehabilitation and help is that of the standards of practice for occupational therapy rehabilitation. The code that supported this category is time and duration of treatment.

a. Time and duration of treatment

During the interviews, the participants were asked to elaborate on the time and duration of the treatment that they have received when they attended their occupational therapy sessions:

P4: *It was once a month. Yes, I felt it was enough and I kept coming. I would be happy if they were increased.*

P5: *Once a week. [Researcher: And how long are you here for?] An hour.*

P6: *It was an hour sometimes 2 hours. It's according to our wish... maybe sometimes I say aii Margaret* 1 hour is not enough for me, give me 1 hour again. She has no problem.*

P7: *I go maybe twice a month. [Researcher: How long is a therapy session?] About 15 minutes, it's not very long.*

*pseudonym

It seems that there was significant variation in the duration and frequency of occupational therapy services received by stroke survivors in the TMHD. Thus, there seem to be no set standards of practice that are followed by occupational therapists in the TMHD. This lack of standards of practice correlates with information that was obtained from the document review (cf. 4.2.2.2.) where it was found that proper monitoring and evaluation strategies are lacking for occupational therapy services.

This aspect also links to the lack of the use of standardized assessments that were identified during the focus group discussion (cf. 4.5.4.1. a). Since no information could be found in the document review on the standards of practice or evidence-based results of occupational therapy services rendered to stroke survivors at PHC clinics, concerns are raised whether the occupational therapy services within PHC in TMHD are applied to its full benefit.

The inconsistencies that have been identified in the service standards for stroke survivors are, however, not new. Reuter *et al.* (2016, pp.7, 8) discovered that there were no clear guidelines for the management of stroke rehabilitation internationally, as different countries are using different guidelines. The *South African guideline for the management of ischemic stroke and transient ischemic attack* (Bryer *et al.* 2010, pp.775–778) provides therapists with guidelines on stroke rehabilitation, but does not provide clear standards of practice that need to be adhered to.

The **lack of standards of practice** calls for further investigation into the required and effective services to stroke survivors on a PHC level. Once a set standards of practice guide is available, it will positively contribute to the procedural and content factors in the design of an occupational therapy stroke program for the PHC setting. The standards of practice is an important factor that will guide the composition and contents of such a program, ensuring that such a program addresses the stroke survivor holistically and according to set norms.

5.3.4. Conclusion

The theme **occupational therapy rehabilitation and help** stresses that the occupational therapist has a vital role to play in the rehabilitation of the stroke survivor. The importance of including the MDT in the design of an occupational therapy stroke program for the PHC setting was highlighted and the content of occupational therapy interventions to stroke survivors was elaborated on. Lastly, inconsistencies in the time and duration of occupational therapy treatment within PHC were highlighted, which raises concerns about the standards of practice for occupational therapy services within PHC. This theme contributed to the objectives of identifying the structural, procedural and content factors that are essential to ensure that occupational therapy intervention for stroke survivors in the TMDH is relevant and feasible. A call is made, among others, to investigate and develop standards of practice for occupational therapy services to stroke survivors within the PHC setting as it is an important procedural factor that will influence the design and relevance of an occupational therapy program for the PHC setting.

5.4. ACCESS TO SERVICES

Another theme that emerged from the interviews with the stroke survivors is access to services. This theme is closely related to the previous theme of occupational therapy rehabilitation and help. This theme focuses more readily on the logistical arrangements of rendering occupational therapy and it comprises two categories, namely the logistical aspects that influence attendance to therapy as well as the personal aspects that influence attendance to therapy. This theme seeks to address the objectives of the structural factors regarding the physical environment available to render occupational therapy services to stroke survivors as well as the challenges stroke survivors experienced while receiving occupational therapy services within a PHC setting.

5.4.1. Logistical aspects that influence attendance to therapy

Themes	Categories	Codes
5.4. Access to services	5.4.1. Logistical aspects that influence attendance to therapy	a) The location of therapy services
		b) The impact of transport costs

The first category that emerged under this theme was that of the logistical aspects that influence attendance to therapy. Two codes were identified within this category, namely the location of therapy services and the impact of transportation costs.

a. The location of therapy services

For stroke survivors to receive the different rehabilitation services that were mentioned in the previous theme, they need to be able to access the therapy. During the interviews the stroke survivors were asked at which location they receive their occupational therapy:

P2: *At the hospital here.*

P4: *I got them here at the clinic. I used a car. If I had to walk right now I wouldn't be able to. It's easy to come with a car and sometimes I am actually scared that I might even fall on the way.*

P5: *Here at this hospital. I don't have a problem I am able to get here.*

P7: *At the clinic in town.*

Some of the participants receive therapy at their PHC clinic while some others receive therapy at the hospital. The majority of the participants were satisfied with these locations at the time of the interviews. One participant voiced that it would be better to receive therapy closer at home. This participant also mentioned that there are a lot of stroke survivors within the community who cannot access therapy at the hospital due to transportation challenges.

The focus group (cf. 4.5.5.2. a) noted it as a concern that often stroke survivors do not have access to therapy services. Although all of the stroke survivors in this study indicated that they were satisfied with where they received therapy, it needs to be kept in mind that these participants were chosen purposefully and that they might not be representative of the broader stroke population.

Access to therapy and the **location** where therapy services are rendered, are two structural factors that will influence the design of an occupational therapy stroke program for the PHC setting, especially for the broader stroke community. These two factors will have a definite impact on where such a program is presented to ensure the accommodation of all the stroke survivors.

b. The impact of transportation costs

Accessing therapy does not only relate to the location from which the services are rendered. Stroke survivors also face transportation costs to reach occupational therapy services at their PHC clinic or hospital:

P1: It becomes very difficult when I don't have transport. I will try and get a taxi. Get some money to get a taxi. It's R80 that they ask for that trip.

P2: They (my family) drive me. They bring me. Transport is not a problem at all.

P4: To come I paid R10, to go back I paid R10.

P5: I pay R200 because I live close to the farm. ...my children are able to help me.

P6: So sometimes transport is a problem. It would be nice if we could get these things at the clinic where it's a bit closer to where we stay. I have heard they say that at the clinic the problem is the space. Because in the township there are a lot of people with stroke and more than anything the issue is transport.

P7: We used to first go to Bethlehem. It used to be R600 to go to Bethlehem and back. At times it is difficult.

Although it was noted from the quotes that transportation costs differ amongst participants, the majority of the participants were faced with considerable expenses for

transportation. This correlates with data obtained from the occupational therapists during the focus group (cf. 4.5.5.2. a).

Although the cost of transportation was not a problem for all of the participants, it is definitely a challenge for many stroke survivors who want to access occupational therapy (and other healthcare services). Evidence from chapter 2 (cf. 2.3.3.) and findings by Naidoo, Van Wyk and Joubert (2017, pp.6, 7), indicate that people living with disabilities in rural areas are experiencing difficulties in accessing and affording transport.

The **costs and availability of transportation** is a structural factor that will influence the design of an occupational therapy stroke program as it has the potential to influence the feasibility of such a program negatively. This factor needs to be considered to ensure equal and affordable access to such a program.

5.4.2. Personal aspects that influence attendance

Themes	Categories	Codes
5.4. Access to help	5.4.2. Personal aspects that influence attendance to therapy	a) The physical energy to attend

The second category that emerged under access to help was that of the personal aspects that influence attendance to therapy. The code that was identified here is the physical energy to attend therapy sessions.

a. The physical energy to attend

During the interviews it also came forward that participants sometimes do not have the physical energy to attend therapy sessions:

P6: Sometimes I feel like exercise is like torturing yourself. And afterwards I feel very tired because of the exercise. ...but to come here one day is like torturing myself. I feel tiredness, weakness for one day like you know when you run one day, tomorrow you are tired. There is nothing you can do.

Vermeer *et al.* (2016, p.7) assume that the loss of energy amongst stroke survivors may be a sign of depression. Terrill, Schwartz and Belagje (2018, p.2) added that stroke survivors can present with both physical and mental fatigue post-stroke and that this fatigue does not resolve spontaneously. This, again, raises the importance of looking out for signs of depression amongst stroke survivors as well as signs of physical fatigue. These aspects need to be incorporated into occupational therapy interventions and it should be addressed timeously.

Signs of depression, fatigue and a loss of energy should be monitored continuously as these are procedural, challenge and content factors that will influence the design of an occupational therapy stroke program for the PHC setting. The program should be structured in such a way that it provides education on and intervention to handle depression, while still making provision to not exhaust stroke survivors.

5.4.3. Conclusion

Access to services stands primarily in the framework of PHC re-engineering (cf. 2.2.3) and, therefore, access to occupational therapy services is vital when identifying structural factors that will influence the design of an occupational therapy stroke program for the PHC setting. The location and the impact of transportation costs are two main structural factors that will influence the logistical arrangements while the physical energy of the stroke survivor will influence the procedural and content factors of such a program. Provision should therefore be made in the design of the program to manage transportation costs and the physical fatigue that stroke survivors are experiencing.

5.5. PERSONAL MEANING AND AGENCY

Covering this last theme, the stroke survivors gave a description of experiences of personal meaning and agency during the interviews. Vik *et al.* (2008, p.265) described agency as the concept where there is an experience of *being in control of daily life*. Lentin (2005, p.192) added that there are eight core aspects of personal agency that includes: "self-determination, self-legislation, meaningfulness, purposefulness,

confidence, active striving, planfulness, and responsibility." Personal agency, therefore, suggests elements of choice as well as the power to act (Bergström *et al.* 2015, p.43).

Although personal agency is important, it is also important to look at agency from a community perspective as this study is based within the PHC community setting. In a paper on community development, Bhattacharyya (2004, p.21) identified three main principles of agency in the community: self-help, felt needs and participation.

With these descriptions of agency in mind, two categories emerged from this theme during the interviews with the stroke survivors. The categories include the personal capacity of the stroke survivor and agency within the stroke survivor population. Each category will be described individually. These categories illuminate vital procedural factors that may impact on the relevance and feasibility of an occupational therapy stroke rehabilitation program, particularly for the PHC setting.

5.5.1. Personal capacity

Themes	Categories	Codes
5.5. Personal Meaning and Agency	5.5.1. Personal capacity	a) The importance of a positive attitude
		b) Making plans

The first category that emerged under the theme of personal meaning and agency is that of personal capacity. This category is supported by two codes, namely the importance of a positive attitude and making plans. Each code will henceforth be discussed.

a. The importance of a positive attitude

During the interviews, the participants expressed the importance of having a positive attitude despite all the burdens and challenges caused by a stroke:

P1: So I did not believe that I would be unable so because of that I have a fighting attitude and I thought that I would be able to. I try and do as many things as possible.

P1: And soon as I did this I was so happy. I said I am now able to sit. I wasn't actually sitting, I was just lifting my body up ever so slightly. But I was still very happy. And that's when I realised that there would be progress.

P6: I've seen it's helpful to speak because a lot of people like to say to me that I am doing well, I am better.

The participants expressed that being positive assists them to cope better and to strive towards more progress. Participant one decided that no one will tell her that she will not be able to walk one day - she persisted in believing that she will be able to walk and she had a fighting attitude to achieve this. Being positive also entails recognising the small victories - even though this participant was not fully sitting, lifting her body was already progress on the road to being able to sit.

Participant six indicated on her turn that positive motivations from other people help to keep her positive. It is important for other people, including community members, relatives and therapists, to acknowledge the progress that stroke survivors make in order to motivate them to keep up a positive spirit and to work hard at their rehabilitation programs.

Personal agency is strengthened by a positive attitude as well as by the ability to choose and the power to act. Being positive and determined to overcome the barriers caused by a stroke, is an integral aspect in the process of agency, as suggested by Vik *et al.* (2009, p.265) and Lentin (2005, p.192).

Keeping up positive spirits and **motivating stroke survivors** are two procedural factors that will influence the design of an occupational therapy stroke program as it will have an influence on the specific occupational therapy intervention that will be designed into such a program. Furthermore, these two factors also advocate for the occupational therapist to foster agency in stroke survivors as it will assist the therapist in working more effectively and it will have a positive effect on the participation of stroke survivors in such a program as well, ultimately leading to better health outcomes.

b. Making plans

During the interviews, it also came forward that stroke survivors are resourceful themselves as they have the ability to make plans with the obstacles that they are struggling with. Although unconventionally long, a narrative was chosen from the interviews to illustrate how resourceful stroke survivors may be:

P1: *So on one day as I was lying. I took a towel. I put it here on my haemorrhagic side. And I put this towel and I worked really hard to put it under my leg. Hold my hand. To put it close to my body. And then to roll onto my side. And that helped me a lot. This thing that I must hold my haemorrhagic leg and roll onto my haemorrhagic side to the right. And then return back to the middle. And while I was pulling the towel. I would pull the pillow. I would put it next to my right side... my haemorrhagic side. So that I could attempt to get up, I wasn't able to get up at that point yet. I struggled a lot. I struggled until the pillow was supporting my haemorrhagic side. And then I held on. And then I used my elbow. And then I worked hard pushing my elbow with lots of tension. And then I would rest. It took a long time with me doing this. And I would take about 2 hours and I wasn't still being able to stand up. Until I got up a little. And soon as I did this I was so happy. I said I am now able to sit. I wasn't actually sitting, I was just lifting my body up ever so slightly. But I was still very happy. And that's when I realised that there would be progress. I just tried, and now you must remember that I wanted to be able to sit. So I used my strong side. So I used my strong side and I would pull on the mattress. And I pulled towards the edge of the bed. And when I was at the edge of the bed. I would want to take off my haemorrhagic leg and that was difficult. I took off my strong one. So as I was doing that I had the idea that let me use my strong leg to use it to push the other. So that it can go off the bed. And I struggled alone. And I wasn't able to but I still used my elbow. And I rested. And I rested at times. And I tried to feel on the bed to where I could actually hold on to. And there was a couch similar to this one we are sitting on. And I wanted to sit there cause it has armrests. I was so scared. I took the pillow and I threw it on the chair. And I took the blanket and put it on there. I took my legs down. I could feel that my left side is very weak. I even prayed. I asked that God to help me. I held on, that I shouldn't fall. And then I went on to my strong side and I rested on the bed. I am worried about my haemorrhagic side trying to get up and to turn. And so the chair wasn't far from the bed. And as I stood up seeing that I was close. I wanted to sit. Now I needed to turn to be able to sit. I struggled until I got to the edge of the chair. And when I was at the edge I am exhausted at this point. And I just thought to myself, if I can just throw myself into the chair. And indeed I threw myself. And fortunately I fell into the chair. And I was struggling to sit. Rested a bit. Held on. Until I was able to sit. I had lots of pain in my haemorrhagic arm. I struggled then I sat. Although I wasn't sitting properly at that time. At least I had sat. My daughter even found me in that position. And when she found me seated like that. Who helped you she asked? And I said to her I helped myself. And she didn't believe, she said is she looking somebody in*

the house or not. And she looked around and realised there was nobody and that I was alone. That's where my progress started from. I started there, I was seated and it was a miracle.

P1: I took my grandchild at 6 months. I looked after him until he was 5. I struggled with the nappy. Until I was able to put it on.

This narrative illustrates that this participant refused to be limited by her physical dysfunctions. She kept on making plans to achieve the goal of sitting that she had set for herself. Her fighting spirit had a positive effect in assisting her to achieve her goals. Furthermore, the reward of achieving these goals has immense value and should be acknowledged.

The ability of the stroke survivor to make plans and to be resourceful should be acknowledged by family members and therapists. This should be done to encourage them to strive towards setting and achieving goals. Opportunities for stroke survivors should be created to assist in solving problems regarding challenges they struggle with, such as ADL. This extract from the interview is an excellent example of how a stroke survivor has turned her challenges into triumphs.

Not only does the making of plans give valuable information towards the opportunities that the occupational therapist can create for the stroke survivor, but it also provides valuable information towards personal agency for the stroke survivor. The ability to make plans links directly to being in control of their daily living as suggested by Vik *et al.* (2009, p.265). Furthermore, the core concepts of agency, as noted by Lentin (2005, p.192), including self-determination, purposefulness, confidence and planfulness, were also portrayed in this section. Bergström *et al.* (2015, p.51) added that enacting agency indicates that a person is making things happen in his/her everyday life, ultimately indicating that agency is a prerequisite for participating in daily life occupations.

Creating opportunities to make and share plans is a procedural factor that will influence the design of an occupational therapy stroke program in the PHC setting and that will urge the occupational therapist to foster agency and resourcefulness amongst stroke survivors purposefully within such a program. Fostering agency has the ultimate goal of restoring control for stroke survivors as well as enabling the power to act.

5.5.2. Agency within the stroke survivor population

Themes	Categories	Codes
5.5. Personal Meaning and Agency	5.5.2. Agency within the stroke survivor population	a) Being able to help others

The second category that emerged within the theme of personal meaning and agency is that of agency in the stroke survivor population. The code that supported this category was: being able to help others.

a. Being able to help others

As mentioned, stroke survivors can be very resourceful as they have walked a path of recovering from a stroke and a lot of lessons have been learnt along the way. During the interviews the stroke survivors voiced that they are able to assist other people:

P1: *I would even volunteer myself. That if I heard that there is someone with a stroke, and I was able to get to there. I would go and motivate that person. And I would say to them they must fight for themselves. That they must bathe themselves, they must do all they can for themselves. They should try at the very least, they shouldn't have an attitude that I am unable, I am unable. [Researcher: I heard that you are very passionate to motivate other people to go and be better.] P1: It is something I desire to do with all my heart. When someone has stroke. I just feel like I should go there so that they do not become a burden to their family.*

P2: *...they (therapists) helped me to go and tell the others and make my own group. I have a group of the elderly, men and women. That come to me. Oh, the people from my church. They are old. They live well. They help me to feel good. Because I have been through a little bit I am able to also then help them.*

P6: *I've seen it's helpful to speak.*

From the verbatim quotes, it is evident that stroke survivors have a need to share their stories with others. They want to go and tell other stroke survivors that life can be different from what they are experiencing now. The stroke survivors have portrayed a desire, not only to feel useful, but also to contribute towards making the lives of others better and easier.

This desire links closely with community agency that was indicated by Bhattacharyya (2004, p.21) as it strives to fulfill felt needs as well as participation among one another. The value of stroke survivors to participate in a community where they can have the opportunity to experience agency (on both a personal and community level) should not be overlooked. Once an opportunity is created for stroke survivors to foster their own agency within a community setting, self-help is also fostered and encouraged amongst them.

The possible use of group therapy and the benefits thereof to share stories has been suggested by the occupational therapists during the focus group (cf. 4.5.4.1. b). When considering a group therapy model to enable stroke survivors to share their stories with one another, Yalom's curative factor of altruism comes to mind. Altruism within a group indicates that participants in the group can make valuable contributions to the group as they can support and motivate one another and also share their problems, suggestions and solutions with one another (Yalom & Leszcz (2005) pp.1, 13). Altruism can further lead to the group participants focusing more on themselves than on the therapist as their self-worth increases and they realize that they have something to (Yalom & Leszcz (2005) pp.1, 13). This is a vital aspect to take into consideration in the design of a program as it can strengthen the therapists' hands and lessen their huge workload, while still providing in the needs of the stroke survivors.

The ability of the stroke survivor to help others is a valuable procedural factor (and asset) that needs to be considered within the design of an occupational therapy stroke program. Not only can such a program be designed to foster agency amongst the stroke survivors, but the hands of the occupational therapist working within the PHC setting are also strengthened where (especially human) resources are scarce. **The use of a group therapy model** is another important procedural factor that has been highlighted in order to reach these goals and to ensure a feasible occupational therapy stroke program for the PHC setting.

5.5.3. The stroke survivor and support groups

Themes	Categories	Codes
5.5. Personal Meaning and Agency	5.5.3. The stroke survivor and support groups	a) The possibility of support groups
		b) Location and access to support groups

The last category that emerged under the theme of personal meaning and agency was the stroke survivor and support groups. This category was supported by two codes, namely: the possibility of support groups and location and access to support groups.

a. The possibility of support groups

During the interviews the possibility to have a support group was raised by all the participants.

P1: *So that we can sit there and speak, and it's important for someone like me. To speak to the ones who got stroke. Because when people are ill. They are difficult, they are stubborn. And they don't want to do anything. And all they do is complain about the aches and pain they have. Personally I would teach them. Demonstrating with water and soap. Show them how actually you could bathe. Because they think when you are haemorrhagic you have to get bathed and it's not like that. You must do it yourself.*

P2: *(A group would be good) Because we are all the same.*

P4: *We will be able to talk about our problems and comfort and encourage each another. ...it will help because when I tell you my problems and you tell me yours whatever it is that we are feeling will be able to be better.*

P5: *I'd participate if we were exercising together. You meet with people and you'd also and continue exercising together because you are exercising where you can get to a better level.*

P6: *I've seen it's helpful to speak. It will be helpful because some other people because it causes them some stress. Because they will feel open to talk about their problems. Cause as a group we will do other things together even things similar to work because when you are at home it feels like it makes you even weaker, it makes your circumstances even worse. In a way that encourages us to do stuff because as they (the therapists) do that. ...it will help us to do things ourselves.*

P7: We would be able to share with one another what to do, how to work all sorts of things.

All the participants had a positive attitude towards a support group. The main theme that surrounds the need for and the positive attitude towards the support groups is the basic human desire to belong and to find solidarity with people who are facing the same struggles. The verbatim quotes clearly indicate that the stroke survivors perceive themselves as being able to help others and to learn from others. The ability of stroke survivors link strongly with agency as discussed in the previous sections (cf. 5.5.1., 5.5.2.) as their need for a support group indicates their need to express felt needs and participation as suggested by Bhattacharyya (2004, p.21). Thus, the possible use of support groups emphasizes the need for the occupational therapist to create opportunities within an occupational therapy stroke program to foster agency amongst stroke survivors, especially within the community setting.

The hands of the occupational therapist will also be strengthened by reaching a bigger population of stroke survivors and creating a bigger opportunity to help and to learn from one another. The ability to utilize support groups as an opportunity to foster agency amongst stroke survivors, is a vital procedural factor and, therefore, an occupational therapy stroke program for the PHC setting should draw strongly on the strengths of the stroke survivors.

As mentioned in section 5.5.2.a, the curative factors come to mind again. Yalom's curative factor of universality comes to mind as it leads to the stroke survivors feeling part of a group that have had the same experiences, rather than feeling alone and isolated (Yalom & Leszcz (2005) pp.1, 6). The feeling of universality usually brings forward a feeling of relief for the stroke survivor (Yalom & Leszcz (2005) pp.1, 6). With this said, the possibility of support groups correlates with information that was shared by the occupational therapists during the focus group (cf. 4.5.4.1. b), who have indicated that group therapy can be of great value to stroke survivors and that the model of group therapy is already implemented in some of the sub-districts of the TMHD.

Stroke survivors would also like to share their stories within a support group, exercise together, give demonstrations on how to do things like washing and comfort and

encourage one another. Mehdizadeh, Mehraban and Zahedyannasab (2017, p.74) explored the effect of group-based occupational therapy on the performance of stroke survivors and they found that ADL presented in a group can be of value with regards to the performance of stroke survivors.

The **possibility of support groups, fostering agency and drawing on the strengths of stroke survivors** support the call of the stroke survivors who participated in this study to have the opportunity to share their progress and ways of doing with other stroke survivors. This need for finding solidarity and to share stories (as well as fostering agency through this) is an important procedural factor that needs to be considered as it will influence the design of an occupational therapy stroke program for the PHC setting by focussing more intensively on the use of a group therapy model.

b. Location and access to support groups

During the interviews the participants were also asked if such a support group would be made available, where an appropriate location would be to host such a group:

P1: *Wherever there is space.*

P2: *Right now ours (group) is at the church. [Researcher: Okay, anywhere else?] Library.*

P4: *Just here at the clinic. Because we don't have another place. [Researcher: Other places?] To have the group at the community hall. Or at the church.*

P5: *It's because we all come from different areas different directions, the hospital is the central point. Yes because that's where all the different people would be able to go to.*

P6: *I have heard they say that at the clinic the problem is the space.*

P7: *Yeah, it would be better at a closer clinic.*

Participants had diverse ideas and opinions regarding a location for support groups. One aspect that came out strongly was that the location needs to have enough space. Another aspect of importance is that the location should be at a central point and closer to where the stroke survivors live.

This correlates with information that was received from the CHWs (cf. 4.4.4.) who have indicated that a stroke program would be best suitable at a PHC clinic or a community hall where it is accessible for stroke survivors. A number of locations have been mentioned by the stroke survivors and the CHWs and further investigation is necessary to explore the feasibility of each location. Some of the options are the PHC clinic, the hospital, a church, the library or the community hall. The **location and access to support groups** is a structural factor that needs to be considered when designing an occupational therapy stroke program for the PHC setting as it will definitely impact the feasibility of such a program as well as the ability of stroke survivors to attend such a program.

5.5.4. Conclusion

Personal meaning and agency is a theme that stands central in the world of the stroke survivor. The occupational therapist has the opportunity to foster agency amongst stroke survivors to allow them to be in control of their own life situations as well as to foster confidence and purpose amongst them. This is a vital factor that is often overlooked and the value thereof misjudged. Fostering agency and strengthening personal meaning for the stroke survivor may, therefore, have a positive influence on the design of an occupational therapy stroke program for the PHC setting, especially as the stroke survivors have expressed that they are resourceful and that they possess strengths, skills and attributes that can be utilized within the broader stroke population. Opportunities should, therefore, be created within such a program to foster, nurture and strengthen these resources of survivors. These resources, embedded within the stroke survivors themselves, can positively contribute to an occupational therapy stroke program for the PHC setting as the stroke survivors can be included in the design as well as in the presentation of such a program.

The importance of a positive attitude, making plans and the ability of stroke survivors to help others should not be overlooked when identifying the procedural factors in the design of an occupational therapy stroke program. By fostering agency and making use of a group therapy model, the hands of the occupational therapist are also

strengthened. The theme of personal meaning and agency brought forward valuable insights toward the procedural factors that will influence the design of an occupational therapy stroke program for the PHC setting.

5.6. CONCLUSION

This chapter has highlighted the value of exploring the views and experiences of stroke survivors. Not only did the information gathered from the stroke survivors support existing knowledge regarding rehabilitation services to stroke survivors, but new information also emerged. Combining existing knowledge and new information provides valuable insights into the factors that will influence the design of an occupational therapy stroke rehabilitation program for the PHC setting, ensuring its relevance and feasibility.

The personal experiences of the post-stroke survivors need to be carefully considered and addressed. The occupational therapist must explain the pathology and the prognosis to the stroke survivor and his/her family, assist the stroke survivor to work through questions such as “Why me?” and the accompanying emotional distress. The physical dysfunctions, loss of roles and the dependence in ADL should also not be overlooked. These aspects are procedural and content factors that call for a holistic approach to be taken when rendering occupational therapy services to stroke survivors.

Apart from the personal experiences of the stroke survivors, attention should be given to the occupational therapy rehabilitation services and the help that stroke survivors are receiving as it influences the procedural factors in the design of an occupational therapy stroke program. This includes involving other members of the MDT team, providing adequate exercises and home programs. The rehabilitation of stroke survivors is however not only a matter between the therapists and the stroke survivor. The importance of involving the families and educating them to support the stroke survivor has important value. The need to develop standards of practice was raised as it will also have an influence on the procedural factors in the design of an occupational therapy stroke program for the PHC setting.

Access to services, that included the location of therapy services and the impact of transportation costs, have raised structural and challenge factors that will influence the design of an occupational therapy stroke program for the PHC setting. Furthermore, the physical energy of stroke survivors to attend therapy sessions as well as the accompanying depression, are procedural and content factors that will influence the design of an occupational therapy stroke program and these need to be considered carefully.

Lastly, this chapter has identified a significant procedural factor that will influence the design of an occupational therapy stroke program for the PHC setting, namely personal meaning and agency. This chapter has highlighted the importance of acknowledging the experiences of the stroke survivors as being valuable assets to the broader stroke population. Stroke survivors own personal capacity as they have the ability to share positive attitudes and make plans to overcome the challenges that they are experiencing. The creation of opportunities by the occupational therapist to foster agency amongst stroke survivors has also been highlighted in order to foster self-help and reinstating control over their daily lives. Stroke survivors are already equipped to help others and the possible use of support groups to encourage agency amongst the stroke survivor population, has been stressed. The possibility of support groups is a procedural factor that will influence the design of an occupational therapy stroke program as it advocates for the use of a group therapy model, simultaneously strengthening the hands of the occupational therapist.

The stroke survivors highlighted valuable structural, procedural, challenge and content factors that need to be considered within the design of an occupational therapy stroke program for the PHC setting, as it will have an influence on the relevance and the feasibility thereof.

Chapter six will henceforth synthesize the factors that have been identified by all the data sets as well as recommendations for future research.

CHAPTER 6: CONCLUSION, IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICE

6.1. INTRODUCTION

The previous two chapters provided the reader with the presentation and discussion of the findings of this study. The PHC system, as well as the perspectives of the health workers and the client (the stroke survivor), was investigated and various factors have been identified that will influence the design of a relevant and feasible occupational therapy stroke program for the PHC setting and thereby seeking to answer the research question of this study:

What are the factors that will influence the relevance and feasibility in the design of an occupational therapy program for stroke survivors within a rural PHC setting in the TMHD?

In the process of answering the research question, the researcher aspired towards making a contribution to the body of knowledge of occupational therapy service delivery to stroke survivors within the PHC setting in the TMHD. This contribution was made in answering the objectives of this study by identifying the factors that will influence the design of such a program, namely: structural and procedural factors as well as factors regarding challenges experienced. As mentioned in chapter 1, an additional objective of content factors related to an occupational therapy stroke program for the PHC setting, strongly surfaced in the study (cf. 1.6.). This chapter will synthesize all the factors that have been identified and implications for practice will be highlighted. Recommendations for future research will also be made through the introduction of a framework for the design of an occupational therapy stroke program for the PHC setting. The limitations and value of this study will also be discussed and this chapter will end with an overall conclusion.

6.2. CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICE: FACTORS IDENTIFIED

This section will aim at providing the reader with a synthesis of the factors that have been identified in the two preceding chapters which will influence the design of an occupational therapy stroke program for the PHC setting. Although it was sought to only provide primary findings, some secondary findings also emerged during this study. The subsections, therefore, not only include the objectives for this study, but other relevant data as well. This section will start with a summary of the factors that have been identified according to the objectives for this study. Thereafter a meta-synthesis of the data will be presented in the form of a framework. It includes three subsections, namely Structural, Procedural, Challenge and Content factors identified; the meta-synthesis of factors; and a conclusion. The conclusions, implications and recommendations will be discussed concurrently for each subsection of the framework.

6.2.1. Structural, Procedural, Challenge and Content factors identified

This subsection will briefly discuss the groups of factors that have been identified and cross-references will be given.

The first group of factors is **structural factors**. The term structural factors indicate the capacity of the health care provider under study (occupational therapy services in the TMDH) in terms of its **facilities**, **resources** and **systems** (Qu *et al.* 2010, p.48; Agency for Healthcare Research and Quality 2011; cf. 1.5.).

Identifying the structural factors aimed at addressing two objectives of this study, namely to describe the structural factors regarding the current regulatory documents in the TMHD on the provisioning of occupational therapy services as well as describing the structural factors regarding the physical environment available to render occupational therapy services to stroke patients within the PHC setting. Although these were the only two objectives that were initially sought to be answered, the data also revealed secondary findings. A third group of structural factors was identified, namely structural factors regarding logistical and resource aspects.

Table 6.1 presents the structural factors that will influence the design of an occupational therapy stroke program for the PHC setting:

Table 6.1: Structural factors identified		
Objectives for the research study	Factors identified	Cross-reference
Structural factors regarding the relevance of the current regulatory documents (including policies, procedures, referral guidelines and human resource plans) in the TMHD on the provisioning of occupational therapy services to stroke patients within the PHC setting.	A lack of the inclusion of occupational therapy in relevant public healthcare documentation.	4.2.2.1. 4.5.3.4. a
	Exclusion of the occupational therapist as part of the multi-disciplinary outreach team in relevant PHC documentation.	4.2.2.1.
	A lack of proper support from policies and higher structures.	4.5.3.4. a
	Poor financial planning and financial resources for occupational therapy.	4.5.3.3. a
	Inadequate resource allocation.	4.5.3.3. a 4.5.3.2. c
	Staffing norms: Human resource constraints and a lack of an adequate number of staff.	4.2.2.2. 4.5.3.1. b 4.5.6.1. a
	Very little information is available on outcome measures as well as the effectiveness of occupational therapy services within PHC.	4.2.2.2. 4.5.4.1. a
Structural factors regarding the physical environment available to render occupational therapy services to stroke patients within the PHC setting.	Inaccessibility of PHC clinics as they do not meet the minimum standards of accessibility for people living with physical disabilities.	4.3.2. 4.5.3.1. 5.2.2. c
	Inaccessibility of the bathrooms at PHC clinics.	4.3.2.
	Unavailability of equipment at the PHC clinics.	4.3.3. 4.5.3.1. 4.5.3.3. b
	Treatment rooms at the PHC clinics are generally very small, the space is inadequate for a wheelchair to enter and turn. None of the clinics observed met the minimum criteria for individual occupational therapy treatment space of 36m ² . Small therapy spaces also limited the exercises that stroke survivors can do.	4.3.3. 5.2.3. a
	A lack of space to render group therapy at the PHC clinics.	4.3.3.
Structural factors regarding logistical and resource aspects that have been identified	Transport is not readily available for occupational therapists to visits PHC clinics on outreach services.	4.5.3.3. b
	The lack of the availability of appropriate assistive devices (such as wheelchairs) will influence the ability of the stroke survivor to access the PHC clinics.	5.3.2. d
	Communication difficulties are experienced as therapists are unable to reach the clinic or the stroke survivor via telephone.	4.5.3.4. b 4.5.6.1. b

The second group of factors that have been identified is **procedural factors**. The term procedural factors indicate the **rehabilitation interventions, preventative and patient education activities** (Qu *et al.* 2010, pp.48, 49) that forms part of occupational therapy service delivery in the TMHD. This section will, therefore, focus on the procedural factors regarding the understanding of the multidisciplinary team on the roles of the

occupational therapist when rendering services to stroke patients within the PHC setting as well as the procedural factors that are essential in ensuring occupational therapy intervention for stroke survivors are relevant and feasible in meeting their health care needs.

Table 6.2 indicates the various procedural factors that have been identified in this study:

Table 6.2: Procedural factors identified		
Objectives for the research study	Factors identified	Cross-reference
Procedural factors regarding the understanding of the multidisciplinary team on the roles of the occupational therapist when rendering services to stroke patients within the PHC setting.	A lack of knowledge amongst CHWs regarding the role of occupational therapy and the service package that can be offered to stroke survivors.	4.4.2. 4.5.3.1. c 4.4.2. 4.5.3.1. c
	Poor referral pathways for occupational therapy.	4.4.2. 4.5.5.1. b
	Involvement of the MDT in such a program is deemed valuable, as well as other team members from inter-sectoral collaborations such as a pastor.	5.3.1. a
	Occupational therapists perceive their efforts are not appropriately recognized.	4.5.3.1.
Procedural factors that are essential in ensuring occupational therapy intervention for stroke survivors are relevant and feasible.	Structural limitations such as policy exclusion, lack of human and financial resources as well as the lack of outcome measures for occupational therapy directly influence the procedural factors negatively.	4.2.2.2. 4.5.4.1. a
	Inadequate follow-up of stroke survivors by the occupational therapists. The majority of stroke survivors have a very poor awareness of occupational therapy's role, resulting in poor adherence and attendance to occupational therapy.	4.2.2.2.
	Inadequate provisioning of assistive devices to stroke survivors.	4.2.2.2. 5.3.2. d
	Occupational therapists' lack of awareness of the challenges that people with disabilities face.	4.2.2.2.
	Occupational therapists' poor cultural comprehension of the population group that they are serving.	4.5.4.1. d
	Assessment of the stroke survivor is important to plan ahead for therapy, however, standardized assessment is not being used by occupational therapists.	4.5.4.1. a
	No standards of practice guide the frequency and timing of occupational therapy sessions.	4.5.4.1. a 5.3.3. a

	No standard is available to measure the quality of therapy that stroke survivors receive.	4.5.4.1. a
	A lack of research and proof on the effectiveness of occupational therapy services in the TMHD.	4.5.4.1. a
	Goals for stroke survivors are individualized and goals aim at addressing the needs of the stroke survivor in a holistic manner.	4.5.4.1. a 5.3.3.a
	Home visits are seen as a potentially positive factor to determine the exact needs of stroke survivors at home.	4.5.1.1. c
	Occupational therapists are involving the family of the stroke survivor and providing family education.	4.5.4.2. a 5.3.2. c
	Occupational therapy aims at assisting stroke survivors and families to take on different roles, including the role of providing therapy related interventions at home.	4.5.4.2. a 5.2.3. a
	Occupational therapists should fulfill the role of motivator for both the stroke survivor and the family.	4.5.4.2. b 5.3.2. c 5.5.1. a
	Home programs are provided to stroke survivors by occupational therapists to address physical dysfunctions through exercise as well as adaptations to ADL.	4.5.5.1. a 5.2.2. c 5.2.5 b 5.3.2. b
	Emotional aspects are included as a core aspect that needs to be addressed with the rehabilitation of the stroke survivor.	5.2.2. b 5.4.2. a
	The possible use of a group program for stroke survivors within PHC.	4.5.4.1. b 5.5.2. b 5.5.3. a
	Include different members of the MDT, including a psychologist and spiritual leader, in the program.	4.5.5.1. a 5.3.1. a
	The occupational therapist can assist in fostering agency amongst the stroke survivors.	5.5.1.a 5.5.1. b 5.5.2. a 5.5.3. a
	Create a space where stroke survivors can share their stories of making plans and having a positive influence on one another.	5.5.1. b

The third group of factors that have been identified is the **challenges** that stroke survivors experience. These challenges will influence the design of an occupational therapy stroke program for the PHC setting.

Table 6.3 indicates the challenge factors that the stroke survivors in this study have identified:

Table 6.3: Factors regarding challenges that stroke survivors experience		
Objectives for the research study	Factors identified	Cross-reference
Challenges stroke patients experienced while receiving occupational therapy services within a PHC setting.	Poor family support systems.	4.4.5.
	Families of stroke survivors find it challenging to take care of stroke survivors.	4.5.5.2. b 5.3.2. c
	It can be challenging for both the stroke survivor and the family to changes roles. Stroke survivors are now dependent on their families to assist them with ADLs.	5.2.3. a
	Stroke survivors have limited knowledge of the benefits of therapy, resulting in poor adherence and follow-up.	4.4.5.
	High transportation costs and the availability thereof to access healthcare services, including occupational therapy.	4.4.5. 4.5.5.2. a 5.4.1. b
	Stroke survivors do not always receive suitable assistive devices.	4.2.2.1. 4.4.5. 4.5.3.3. a 5.3.2. d
	Stroke survivors are experiencing emotional distress and depression.	5.2.2. b 5.2.3. a
	Stroke survivors are burdened with a number of physical dysfunctions and disabilities.	5.2.2. c
	Stroke survivors are experiencing challenges with regard to financial burdens.	5.2.3. a
	Stroke survivors do not always have the physical energy to attend therapy sessions.	5.4.2. a

The last group of factors that have been identified is **content**. As mentioned previously, content factors arose unavoidably during data collection as secondary findings. In order to design a holistic program that will be relevant and feasible for the stroke survivor within PHC, these factors are vital to be considered and included in the design of such a program.

Table 6.4 provides an overview of the content factors that have been identified in this study:

Table 6.4: Factors regarding content identified		
Objectives for the research study	Factors identified	Cross-reference
Factors identified regarding content that will influence the design of an occupational therapy stroke program for the PHC setting.	Provide the necessary insight into the pathology and the prognosis.	4.5.4.2. b 5.2.1. a 5.3.2. c
	Assist stroke survivors to work through the grieving process.	4.5.4.2. b 4.5.5.1. a
	Prepare and assist the stroke survivor to accept and integrate into the patient role as well as to handle the loss of previous roles.	4.5.5.1. a 5.2.3. a
	Address the loss of income and the accompanying financial burden that stroke survivors are experiencing (skills training).	4.5.5.1.a 5.2.3. a
	Provide information to stroke survivors and their families on disability rights and how to handle the stroke survivors at home.	4.5.5.2. b 5.3.2. c
	Include the management of emotional distress and especially the management of depression into the groups	4.5.5.1. a 5.2.1. a 5.2.2. a 5.2.3. a 5.4.2. a
	Address existential questions of the stroke survivors like "why me?"	5.2.2. a
	Include exercises within the stroke program.	5.3.2. a
	Address problems with physical dysfunctions and difficulties with participating in ADLs.	5.2.2. c 5.2.3. b
	Home programs can complement the stroke program	5.3.2. b
Fostering advocacy as a core concept.	5.5.1. a 5.5.1. b	

This subsection aimed at merely providing a summary of the factors that have been identified, while the following subsection will conclude with a synthesis of these factors.

6.2.2. Meta-synthesis of factors

The meta-synthesis is presented as a framework that can be used to design an occupational therapy program for stroke survivors within the PHC setting in the TMHD. Figure 6.1 represents the framework.

The Framework consists of two main categories, namely **establishing relevance and feasibility of a program** and **design specifications and requirements** (cf. 3.4.). The design specifications and requirements are further divided into two subsections, namely **factors influencing design** and **factors influencing program delivery**.

Each section of the framework will be presented according to the conclusions that were drawn, the implications and the recommendations for practice.

6.2.2.1. Relevance and feasibility

The first section of the framework represents the relevance and feasibility that needs to be established prior to the design of an occupational therapy stroke program for the PHC setting. In order for such a program to be designed effectively and be implementable in the future, the relevance of such a program should be demonstrated. Furthermore, the feasibility of such a program should be established in order to address the risks that may hinder the feasibility and implementation of the program in the future.

As was determined in the preceding chapters, there is an increase in the number of stroke survivors that are in need of occupational therapy rehabilitation in the TMHD (cf. 2.4.2), affirming the need for an occupational therapy stroke program. A number of factors have indicated the relevance and need of an occupational therapy stroke program for the PHC setting. These factors include, but are not limited to, the following:

- The lack of outcome measures for occupational therapy service delivery to stroke survivors within the PHC setting (cf. 4.2.2.2., 4.3.3., 4.5.4.1. a).
- The lack of evidence and standards of practice to prove the effectiveness of occupational therapy service delivery within the PHC setting (cf. 4.5.4.1. a).

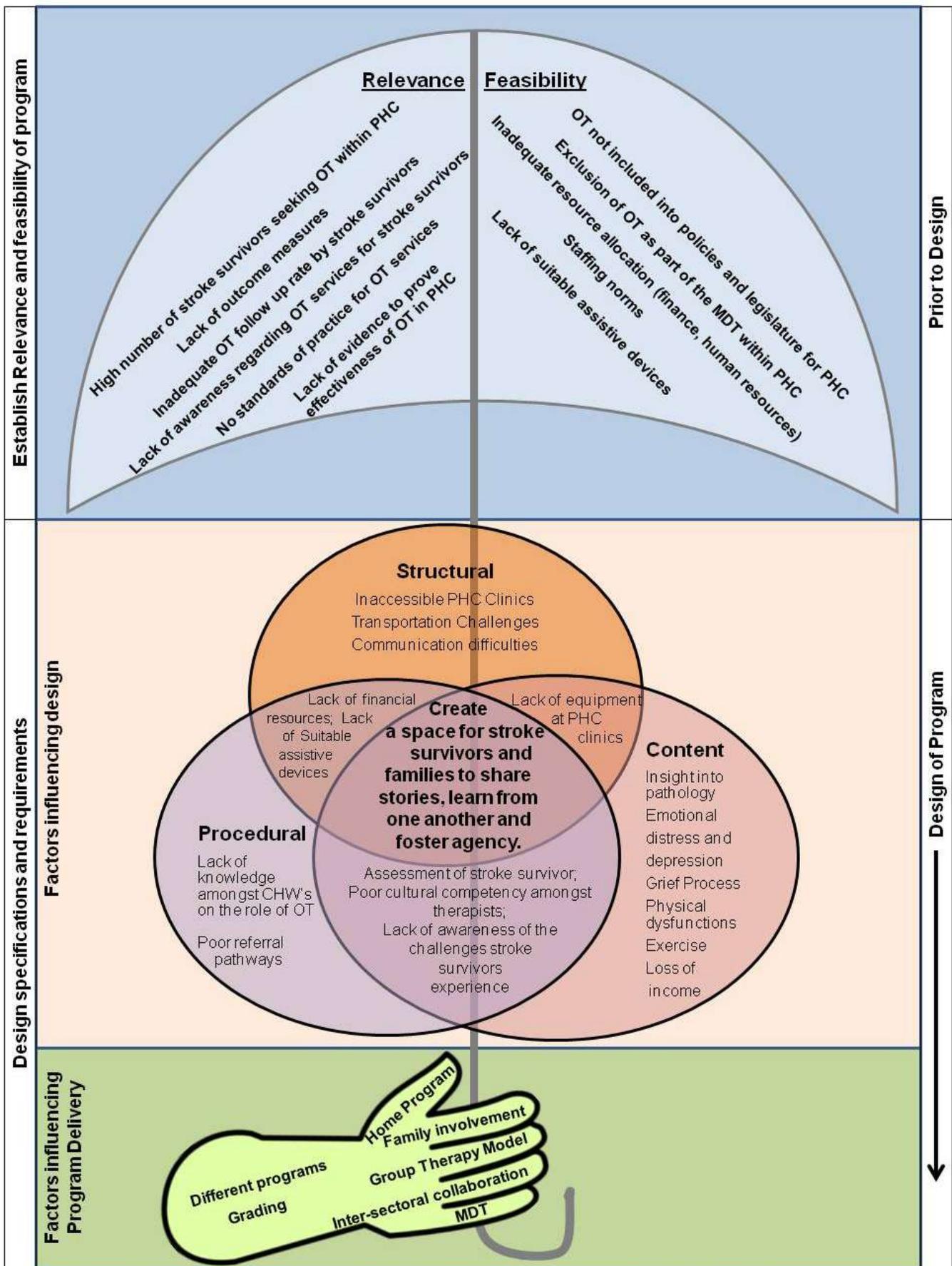


Figure 6.1: A Framework for the design of an occupational therapy stroke program for the PHC setting

- A lack of research and evidence-based proof on the effectiveness of current models of occupational therapy service delivery to stroke survivors at the PHC clinics in the TMHD (cf. 4.5.4.1. a).
- The inadequate follow-up of stroke survivors to attend therapy sessions (cf. 4.2.2.2.) as a result of poor availability of the occupational therapy service (cf. 1.1., 2.3.1.).
- A poor awareness amongst stroke survivors regarding the role of occupational therapy in stroke rehabilitation (cf. 4.2.2.2., 4.4.5.).

These factors imply that the design of an occupational therapy stroke program for the PHC setting may assist in developing outcome measures and evidence-based practice models for the rendering of occupational therapy to stroke survivors within PHC. These factors further imply the necessity of further research on evidence-based occupational therapy practices within the PHC setting as well as the importance of educating stroke survivors on the important role that occupational therapy can play in their rehabilitation process. These factors lastly imply that the design of an occupational therapy stroke program should explore the different models of therapy that are currently provided to stroke survivors within PHC in order to develop guidelines on the assessment of the chronic stroke survivors, the timing and frequency of such a program.

The results of this study, therefore, support the need for **outcome measures to be sourced or developed for the rendering of occupational therapy services to stroke survivors within the PHC setting**. These outcome measures can be developed concurrently with the design of an occupational therapy stroke program, as it will assist to measure the outcomes targeted by such a program. The results further indicate the need to develop a **set list of standards of practice for occupational therapy service delivery to stroke survivors within PHC to allow for the evaluation and monitoring of occupational therapy services to stroke survivors in the PHC setting**. The results also **advocate for the education amongst and motivating of stroke survivors and members of the MDT** on the benefits (cf. 2.4.2., 4.4.3.) that an occupational therapy stroke program may have for stroke survivors. Lastly, further research is, therefore, recommended as it is necessary to **determine the effectiveness of current occupational therapy interventions** within PHC in the TMHD.

While the preceding paragraphs focused on the relevance of an occupational therapy stroke program for the PHC setting, the focus will now shift to the feasibility of such a program. The factors that have been identified that threaten to inhibit the feasibility of an occupational therapy stroke program include:

- The exclusion of occupational therapy from relevant public health care documentation as well as occupational therapy not considered as part of the outreach team within PHC (cf. 2.2.3.1., 4.2.2.1., 4.5.3.4. a).
- The lack of sufficient financial and other resource allocation (cf. 4.5.3.3. a, 4.5.3.2. c).
- Human resource constraints and the lack of an adequate number of staff (cf. 4.2.2.2., 4.5.3.1. b, 4.5.6.1. a).
- Stroke survivors do not always receive adequate assistive devices such as wheelchairs (cf. 4.2.2.2., 5.3.2. d, 6.2.1.).

These factors imply that occupational therapy as a profession and ultimately the design of an occupational therapy stroke program for the PHC setting, may not receive the necessary support from higher structures of the governing body of the public healthcare system. The lack of policy inclusion and the lack of recognition of occupational therapy as part of the outreach team, may pose risks for the future implementation of an occupational stroke program for the PHC setting. These factors, further, imply the possible lack of sufficient resource allocation (financial and human resources) to present an occupational therapy stroke program to stroke survivors in the PHC setting and, therefore, the possible inclusion of CHWs in the presentation of an occupational therapy stroke program should be explored (cf. 4.4.2., 4.5.6.1. b). It is, however, important to remember that CHWs are not formally trained (cf. 2.2.3.1.) and this implies that if an occupational therapy stroke program is to be presented by CHWs, a formal training program should be developed together with the occupational therapy program to ensure the CHWs are equipped appropriately to present such a program. Lastly, these factors imply a risk for the implementation of an occupational therapy stroke program as stroke survivors may not be able to attend the program due to the lack of assistive devices, possibly resulting in a high defaulter rate. An occupational therapy

stroke program should, therefore, prevent a high defaulting rate by including the issuing of assistive devices. Even though these factors imply risks toward the implementation of an occupational therapy stroke program, the value and need for occupational therapy services at a PHC level was evident (cf. 4.4.3., 5.5.3. a) and, the possibility of designing a program that can overcome these challenges, exists.

The results indicate that **managerial support (on a district, provincial and national level) and buy-in from PHC stakeholders should be sought** to ensure the effective implementation of an occupational therapy stroke program for the PHC setting in the future. Once the relevant stakeholders buy into the importance of the rendering of occupational therapy services on a PHC level, financial and human resources can be sought and the role of the occupational therapist in the management of the stroke survivor, can be recognized. Derived from the results of this research, it is, therefore, recommended that occupational therapy staff employed within the public health sector, should **advocate for the inclusion of occupational therapy services in the relevant public healthcare policy and legislation**. Furthermore, all therapists (working in all levels of care) should be committed to **demonstrating evidence-based practice** with stroke survivors through proper documentation and researching of practice-based occupational therapy services for stroke survivors (cf. 2.4.2.). It is known that budget constraints are a given within the PHC setting (cf. 2.2.2.), advocating for human and financial resources may be beneficial, but it may not necessarily serve as the solitary solution. It is, therefore, also recommended that **alternative options should be explored in the presentation** of such a program, such as making use of cost-effective interventions and researching the possible inclusion and training of CHWs to present the program (cf. 4.4.2., 4.5.6. b), in order to account for the unavailability of sufficient occupational therapy staff on a PHC level. Occupational therapists are urged to think creatively on how financial resources are spent and how resources can be re-used to ensure optimal resource use and management.

All of the above-mentioned factors supported the relevance and need for an occupational therapy stroke program for the PHC setting. While risks for the feasibility and implementation of such a program have been highlighted, the following subsection

will focus on the factors that will influence the design of the program and it will also provide alternatives to counteract the risks identified.

6.2.2.2. Factors influencing design

The second section of the framework (cf. Figure 6.1) represents the factors that will influence the design of an occupational therapy stroke program for the PHC setting. These factors include the **structural, procedural** and **content** domains. As these factors are closely related, the domains overlap and, therefore, additional domains emerged namely structural-procedural, structural-content, procedural-content and structure-procedure-content. Each domain contains a number of factors that have been identified in this study and the factors will be discussed according to the conclusions that were drawn, the implications and the recommendations for practice.

6.2.2.2.1. Structural

The first factor within the structural domain is the **inaccessibility of the PHC clinics** as the PHC clinics do not meet the standards for accessibility requirements (cf. 4.3.2., 4.5.3.1.). The inaccessibility of the PHC clinics implies that additional options for venues should be sought. This problem should also be elevated **to a provincial and national level to inform the relevant managerial structures of the challenges that are experienced on grass root level as well as to prevent the building of inaccessible PHC clinics in the future.** This challenge should further be elevated in order to **request structural changes** to the existing PHC clinics. Structural changes to the PHC clinics will not only be to the benefit of a future occupational therapy stroke program, but it is an important issue that needs to be addressed as it affects all patients with disabilities who are making use of PHC clinics in the TMHD.

The second and third factors under this domain relate to **logistical** and **resource** aspects. This study has identified that transport is not readily available for occupational therapists who embark on clinic outreach visits and that telephones are not always working to communicate with clinic staff and stroke survivors (cf. 4.5.3.3. b, 4.5.3.4. b, 4.5.6.1. b). These factors imply a number of challenges in the presentation of an occupational therapy stroke program, as there might be difficulties in reaching the

venues and communicating with the relevant stakeholders. These factors further imply that such a program should make provision for the transportation of therapists or other presenters, as well as access to effective communication strategies to communicate with PHC stakeholders.

The results, therefore, indicate that occupational therapy staff should **motivate and request an allocated vehicle** (in conjunction with policy inclusion cf. 6.2.2.1.) **that will be used for the sole purpose of providing occupational therapy outreach services to PHC** which can be used for the presentation and implementation of an occupational therapy stroke program.

Transportation was not only noted as a challenge for occupational therapists working within the PHC setting, but one of the biggest challenges for stroke survivors is the exorbitant transportation costs to attend therapy sessions (cf. 4.4.5., 4.5.5.2 a). This factor implies that if the transportation challenge is not adequately addressed, an occupational therapy stroke program for the PHC setting will not be feasible as stroke survivors will not be able to attend such a program. It further also implies possible poor adherence to and follow-up in an occupational therapy stroke program. This challenge can, however, not be addressed by the health sector alone and needs the collaboration of various stakeholders such as the local municipality and the local taxi associations.

The results firstly suggest that an occupational therapy stroke program should be **presented as close to the stroke survivor's home environment as possible**, with the aim of avoiding long travelling distances and high transportation costs. Secondly, the results suggest that the **health sector, together with public transport associations, should seek solutions to this challenge**. An **intersectoral approach** should be taken to ensure that stroke survivors have access to accessible and affordable transportation services.

The aforementioned structural factors will have a definite influence on the design of an occupational therapy stroke program for the PHC setting, as it will influence the feasibility of such a program.

6.2.2.2.2. Procedural

The second domain of factors that will influence the design of an occupational therapy stroke program for the PHC setting is that of **procedural factors**. The first factor under the procedural domain is the lack of knowledge amongst the MDT, in particular the CHWs, on the role of occupational therapy in stroke rehabilitation (cf. 4.4.2., 4.5.3.1. c) as well as on the referral pathways to occupational therapy. This is a vital factor to consider and address as the possible inclusion of CHWs in an occupational therapy stroke program for the PHC setting (cf. 6.2.2.1.), was suggested. This factor implies that the PHC outreach team should be educated to ensure that all team members are aware, not only of the occupational therapy service package, but also of the referral pathways to ensure that stroke survivors are referred correctly for occupational therapy. Only once all stakeholders are properly informed of the roles and value of the occupational therapy services within PHC, support can be given by all stakeholders to an occupational therapy stroke program. This factor further implies that, should CHWs be included in the presentation of an occupational therapy stroke program, CHWs should be thoroughly trained in the services that occupational therapists can offer stroke survivors and the benefits of these services to the health and wellbeing of the stroke survivors and their families.

The results, therefore, suggest that occupational therapists in the TMHD should **educate and inform CHWs and other role players within PHC on the roles of occupational therapy within PHC** as well as on the **service package and benefits that occupational therapists can offer stroke survivors** (cf. 2.4.2.). The development of outcome measures for occupational therapy service delivery within PHC (cf. 6.2.2.1.), may assist in demonstrating and communicating the value of occupational therapy to stroke survivors and other role players within PHC. It is, however, vital to remember that this should be done by making use of evidence-based practices to portray the value of occupational therapy within the PHC setting (cf. 6.2.1.). Once all stakeholders are aware of the role of the occupational therapist, poor referral pathways may be minimized and it will undoubtedly support the execution of an occupational therapy stroke program for the PHC setting in the future.

The procedural factors that have been identified will have a definite impact on how an occupational therapy stroke program will be presented within the PHC setting.

6.2.2.2.3. Content

The third domain of factors that will influence the design of an occupational therapy stroke program for the PHC setting is the **content factors** of such a program. From Table 6.4 it is evident that stroke survivors are burdened with a number of physical and emotional dysfunctions after suffering the stroke (cf. 2.4.1., 5.2.1., 5.2.3., 5.2.4., 6.2.1.). Stroke survivors might also not have the physical energy to participate in therapy sessions, possibly due to underlying depression (cf. 5.4.3.). These are core factors that imply that the emotional and physical needs of stroke survivors should be addressed within an occupational therapy stroke program for the PHC setting. Another factor that influences the content of an occupational therapy stroke program, is the loss of income and the financial burdens (cf. 5.3.2. a) that stroke survivors are facing. The loss of income that stroke survivors experience does not only influence the ability of the stroke survivor to attend occupational therapy sessions, but it also has a devastating effect on the quality of life of the stroke survivor.

Even though the content factors were not researched extensively in this study, the results, therefore, recommend that an occupational therapy stroke program should not only address the **physical and emotional needs** of the stroke survivor, but the **loss of income should be addressed as part of the content of an occupational therapy stroke program** for the PHC setting. Interventions may include exercises to maintain the physical level of functioning and methods of generating an income as well as skills training. Furthermore, an occupational therapy stroke program may also address topics on **stroke pathology, depression, emotional distress, working through the grieving process and addressing financial burdens**. It is, however, recommended that more **research should be done on the exact content** that needs to be introduced in the program to address the physical and emotional needs of stroke survivors.

Further investigation into the content factors in the design of an occupational therapy stroke program for the PHC setting is vital to ensure that such a program will be

comprehensive, relevant and feasible, ultimately ensuring that the needs of the stroke survivor and their families are addressed in a holistic manner. Lastly, the results suggest that the design of an occupational therapy stroke program should **contain proper guidelines on each session** that will be presented, and that it includes the goals, outcomes, activities, timing/duration and resources that will be needed to present such a program. These aspects are vital to ensure that the program is user-friendly and implemented effectively.

6.2.2.2.4. Structural-procedural

The first overlapping domains that will influence the design of an occupational therapy stroke program, is that of **structural and procedural factors**. It is vital to note that the structural factors (cf. 4.2.2.2., 4.5.3., 6.2.1.) will undoubtedly have an influence on the procedural factors in the design of such a program, as the lack of inclusion in policy and the accompanying lack of financial and human resources, may have a negative influence on occupational therapy service delivery to stroke survivors within the PHC setting.

The first structural-procedural factor has been identified as the unavailability of suitable assistive devices (cf. 4.2.2.1., 4.4.5., 4.5.3.3. a) that are not only limited to wheelchairs, but includes assistive devices for activities of daily living. The unavailability of suitable assistive devices originates from the lack of financial resources (cf. 6.2.2.1.). The results suggest that an occupational therapy stroke program should make provision to support and supply stroke survivors with the necessary assistive devices, however, due to the financial constraints in the public healthcare system, this factor implies that proper planning should be done within the design of such a program to include home-made, low-cost assistive devices (including wheelchairs and assistive devices for ADL).

The results, therefore, imply that an occupational therapy stroke program for the PHC setting should make provision to assist stroke survivors with the necessary assistive devices and that the occupational therapist should **train the stroke survivors and their families how to use** such devices as well as how to **make cost-effective devices** at home. It will, therefore, be vital for the presenters of such a program (possible CHWs) to

be able to identify and refer stroke survivors in need of assistive devices to an occupational therapist. It is, however, important to note that the provisioning of assistive devices is a service that should already be rendered by the occupational therapist on a PHC level and should not be seen as a new service element.

6.2.2.2.5. Structural-content

The second overlapping of domains is found between the **structural and content** domains. One factor has been identified in the overlap of these two domains, namely the unavailability of relevant equipment within the PHC clinics to render occupational therapy services (cf. 4.3.3., 4.5.3.1.). The unavailability of equipment at the PHC clinics poses a major challenge for the presentation of an occupational therapy stroke program, as it influences the feasibility and structuring of the content of such a program.

As a result, the program could be designed in one of two ways. Firstly, the program can be designed in such a manner that all the **equipment that is needed can be included into a *program kit*** and that such a kit can be portable for the use in multiple clinics or, secondly, that the program can be designed to **require minimal to no use of equipment**. If the use of a *program kit* is considered, each sub-district will be supplied with such a kit to allow outreach to the clinics. Due to the low staffing norms, the possibility of more than one therapist conducting outreach within a sub-district, is very small. Therefore, one kit per sub-district should be sufficient. Both these suggestions need to be researched further, however, both have advantages. The portable kits will limit the costs of procuring new equipment for each PHC clinic, while a program requiring no equipment will have no financial implication. Should the use of a program kit be explored, such a kit should be **easily manageable and easily accessible** for the presenters in order to ensure that the kit is taken with them to clinics and utilized effectively. Since occupational therapy outreach services will still continue, regardless of the design of an occupational therapy stroke program, it is recommended that occupational therapists should seek creative and innovative ways of overcoming the barrier of the lack of equipment at PHC clinics. The adaptability of occupational therapists is the key and additional ways of rendering services can be explored.

6.2.2.2.6. Procedural-content

The third group of overlapping domains is that of the **procedural and content** factors. The content that will be included in an occupational therapy stroke program is directly dependent on the procedural factors in the delivery of occupational therapy services within the PHC setting. Three main factors have been identified that will influence both the procedural and content domains namely, the assessment of the stroke survivor, the poor cultural competency amongst occupational therapists as well as the lack of awareness of the challenges that stroke survivors experience.

Firstly, the assessment of the stroke survivor will have a direct influence on the content of an occupational therapy stroke program that will be presented to the stroke survivor, as mentioned under 6.2.2.1. In order to provide a holistic and thorough service to stroke survivors, it is essential to fully understand the needs of the stroke survivors. According to the results of this study, occupational therapists are assessing stroke survivors and goals are individually set to ensure that their needs are met in a holistic manner (cf. 4.5.4.1. a, 5.3.3. a). This factor implies that an occupational therapy stroke program should make provision for the assessment of the stroke survivor and it further implies that such a program should also make provision to address the different needs of stroke survivors (cf. 5.2.2. c). This factor may imply that adaptable programs may be developed for the stroke survivors with activities that can be graded according to the level of functioning of each stroke survivor.

The results of this study suggest that **more research should be done in relation to the content factors** that will influence the design of an occupational therapy stroke program for the PHC setting. It is vital to **explore the exact needs of stroke survivors**, as this study only focused on chronic stroke survivors and is thus not representative of the bigger stroke population. Gaining an in-depth understanding of the needs of stroke survivors will be essential to ensure that the content of an occupational therapy stroke program for the PHC setting will be relevant and meeting the needs of all stroke survivors in a holistic manner.

The results of this study have further identified that occupational therapists are not always aware of the cultural aspects and the challenges that people with disabilities face (cf. 4.2.2.2., 4.5.4.1. d). This factor implies that an occupational therapy stroke program cannot be only designed by occupational therapy staff, but that the views of the stroke survivors and their families are crucial to take into consideration. The results, therefore, concludes that the future design of an occupational therapy stroke program for the PHC setting needs to be done by occupational therapists in conjunction with stroke survivors in order to ensure that the content of such a program will be culturally relevant by addressing the views, experiences and challenges of the stroke survivor population of the TMHD.

6.2.2.2.7. Structure-procedure-content

The last overlap between domains involves all three domains namely the **structural, procedural and content** domains. Creating a space for stroke survivors and their families to receive support, share their stories with one another and foster agency, has strongly emerged as the centre of all the domains. The results of this study have suggested that the families of stroke survivors are already involved in occupational therapy sessions in the TMHD (cf. 4.5.4.2. a, 5.3.2. c) and it was noted that some occupational therapists are already implemented group therapy as a means of providing services to stroke survivors within PHC (cf. 4.5.4.1. b, 5.5.3. a). The use of a group therapy model is, therefore, recommended (cf. 4.2.2.2., 6.2.1.), since **agency can be fostered** (cf. 5.5.2. a) by stroke survivors supporting one another within a group setting. It is, however, important to note that a group format will only be desirable once acute, individual occupational therapy is concluded.

6.2.2.3. Factors influencing program delivery

The last section of the framework represents the factors that influence the program delivery of an occupational therapy stroke program for the PHC setting. These are the factors that have been identified that provide guidelines on how the delivery of such a program could be designed in future research.

Firstly, as mentioned in section 6.2.2.2.6., stroke survivors have different and individualised needs. Therefore, an occupational therapy stroke program should be **adaptable** and **examples of grading should be included** in all activities to ensure that the program is user-friendly for the presenters. Other factors that have been identified include the use of home programs and involvement of the family in the program. The results of this study have indicated that families are involved in the rehabilitation of stroke survivors (cf. 4.5.4.2. a, 5.3.2. c; 6.2.2.2.7.) and that therapists assist families to take on different roles (cf. 4.5.4.2. a, 5.3.2. c), especially the role of providing therapeutic interventions at home through a home program (cf. 4.5.5.1. a, 5.3.2. b). These factors support previous recommendations (cf. 6.2.2.2.7.) and advocate for the inclusion of family members in the delivery of an occupational therapy stroke program.

The results of this study, therefore, suggest that **specific attention should be given to educating and teaching the families of stroke survivors' in taking care of the stroke survivor at home, whilst accommodating the emotional needs of both the stroke survivor and their family members.** Furthermore, the use of **home programs** can be explored within the design of an occupational therapy stroke program to ensure that the necessary information is transferred to the home environment.

Another factor that will influence the delivery of an occupational therapy stroke program in the PHC setting is the use of a group therapy model as discussed earlier (cf. 6.2.2.2.7.). The use of group therapy is indicated as a method of occupational therapy service delivery within PHC (cf. 2.3.1) and it may have benefits within the PHC setting, particularly in overcoming the challenge of low staff numbers. Previous recommendations have been made to include the CHWs in the presentation of an occupational therapy stroke rehabilitation program (cf. 4.4.2., 4.5.6., 6.2.2.1.) and the CHWs have indicated that they will be willing to present such a group if they receive adequate training (cf. 4.4.2.). The results, therefore, emphasize the possibility of designing an **occupational therapy stroke program for the PHC setting in a group therapy format and training CHWs to present such a program.**

The utilization of intersectoral collaboration has also been identified as a factor that will influence the delivery of an occupational therapy stroke program, since PHC clinics do not offer any space for the presentation of such groups (cf. 4.3.3., 6.2.2.2.1.). The need for additional venue options is, therefore, highlighted.

The results of this study indicate that **intersectoral collaboration should be explored and the possibility of using facilities from other government departments (such as the local municipality) or community stakeholders should be explored.** Possible facilities might include **churches, community halls, or hospitals** (cf. 4.4.4., 5.4.1. a, 5.5.3. b.). It is, however, of vital importance that all of these venues **should be assessed and evaluated for accessibility of people with disabilities** before a decision is made. It is foreseen that different communities might use different facilities and that the venues for an occupational therapy stroke program, might differ amongst communities.

The last factor that will influence the delivery of an occupational therapy stroke program for the PHC setting is the inclusion of the MDT. The results of this study have indicated that different members of the MDT can be involved in the presentation of an occupational therapy stroke program (cf. 5.3.1. a), indicating that the involvement of the MDT should be explored to determine the value that each member can contribute to such a program. The MDT members that are essential in the management of stroke survivors include the speech therapist, physiotherapist, psychologist, medical doctor, orthotist, registered nurse as well as a CHW.

The results of this study, therefore, suggest the **inclusion of members of the MDT team and community stakeholders in the design of an occupational therapy stroke program for the PHC setting.** The inclusion of the MDT may lead to the design of a multidisciplinary stroke program in the future, fitting the ethos of PHC.

6.2.3. Conclusion

In conclusion, the preceding subsections together with the Framework for the design of an occupational therapy stroke program for the PHC setting (cf. Figure 6.1), has reiterated the relevance of an occupational therapy stroke program for the PHC setting

in the TMHD. Although a number of risks have been identified that may influence the feasibility of such a program, creative solutions were sought to overcome these risks. The preceding subsections have demonstrated the importance of synthesizing the various structural, procedural and content factors to ensure that an occupational therapy stroke program is designed from a holistic perspective, taking into consideration all of the influencing factors. The synthesis found within the framework (cf. Figure 6.1), has laid the foundation from which a relevant and feasible occupational therapy stroke program can be designed, while it has further reiterated the need to think afresh on how stroke survivors are managed within the PHC setting. Ample opportunities lie within the design of an occupational therapy stroke program to re-engineer the current models of service delivery within the PHC setting. An occupational therapy stroke program will not only be to the benefit of the stroke survivors, but it has the potential to be to the benefit of all stakeholders involved within the PHC setting. .

6.3.RECOMMENDATIONS FOR FUTURE RESEARCH

Even though this study has answered the research question and has met the objectives that were set, the work is not yet complete. Shortcomings and challenges regarding the delivery of occupational therapy services within the PHC setting in the TMHD have emerged during this study which calls for further investigation. Further research is desirable to achieve the goal that has been set by the NDoH to make health care services accessible to all within the PHC setting (cf. 2.2.3.), as well as to assist with the implementation of NHI (cf. 2.2.5.).

As this study made use of the DSR methodology and framework, ample opportunities are offered to engage in further research. Only phase 1 of the DSR methodology has been executed in this study (c.f. 2.2.3.). It is, therefore, recommended that phase 2 and 3 of the DSR methodology should be executed in future research in order to complete the process of designing and evaluating an occupational therapy stroke rehabilitation program (cf. Figure 3.1). The following recommendations are made for future research regarding the design of the program:

- It is recommended that the **content factors** of such a program, as stated in section 6.2.4., should be researched and explored further to determine an exact description of content. These include, to only name a few: exercises (cf. 5.3.2. a), home programs (cf. 5.3.2. b) and family education (cf. 5.3.2. c).
- Once content factors have been further explored and synthesized with the results of this study, a **reiterative design process** should commence by designing a group occupational therapy stroke program for the PHC setting.
- **Various stakeholders** should be included in the design process of the program inclusive of stroke survivors, family members of the stroke survivors, occupational therapy staff employed within PHC, members of the MDT (medical officers, registered nurses, extended rehabilitation team members, relevant managerial structures and policy makers). Local government and churches could also be included in the design of such a program, aiming to achieve intersectoral collaboration.
- Once a final draft program has been designed, it is recommended that the draft should be **implemented and evaluated** for its feasibility within the PHC sector.

Apart from continuing with the DSR process, other recommendations are made for occupational therapy practice within the PHC setting:

- Further research is necessary to evaluate the **current level of efficacy** of occupational therapy services to stroke survivors (cf. 4.3.3., 4.5.4.1. a, 5.3.3. a) as there is a lack of contextual evidence. A **set standard of practice** as well as an **evaluation and monitoring tool** for occupational therapy service delivery to stroke survivors in PHC should be compiled to assess the effectiveness of occupational therapy services to stroke survivors.
- Research should be done to establish the aspects/measures that need to be implemented to prevent occupational therapists within PHC from **feeling overworked and underappreciated** (cf. 4.5.3.2. a).

- Research should be done to explore the possible use and implementation of a **mobile rehab clinic** (cf. 4.5.6.2. a).
- Research should be done to explore the feasibility and relevance of establishing **care centres** for stroke survivors who are in need of full-time care (cf. 4.5.6.2. b).
- The use of an **MDT** approach for the rendering of rehabilitation services within the PHC setting to stroke survivors should be researched and the efficacy thereof should be determined (cf. 5.3.1. a).

6.4. LIMITATIONS OF THIS STUDY

The following aspects were limitations of the current study:

- This research study was conducted in a particular context hence the findings of this study can only be generalized to the TMHD. Although this study is not generalizable to the broader stroke population in the Free State or SA, it offers valuable insights for future research that can be conducted amongst stroke survivors in the PHC setting.
- Due to time and financial constraints, only seven PHC clinics were visited for the structured observations at the clinics. It is recommended that a bigger sample of clinics be visited for future studies to allow for a more accurate representation of the stance of all PHC clinics regarding accessibility in the TMHD.
- The structured interviews with the CHWs may have limited the richness of knowledge that could have been received from this participation group. It is recommended that qualitative research be considered with the CHWs for future studies when designing an occupational therapy stroke program for the PHC setting.
- The focus group consisted of a very small group of four female occupational therapists. However, at the time that the research was conducted, only seven occupational therapists were permanently employed in the TMHD of which the researcher was one. The group of occupational therapists cannot be representative

of all the occupational therapists working within PHC in SA and the data from the focus group are only contextually relevant to the TMHD.

- A very small population of stroke survivors has been included in this study. The stroke survivors were chosen purposefully and were not representative of the broader stroke population. Member checking of the stroke survivors was also not feasible in this study as the researcher was unable to trace and locate the stroke survivors again. The reason for being unable to trace the stroke survivors included that one of the therapists resigned, breaking contact with two participants. Other therapists were unable to contact the stroke survivors due to changed telephone numbers.
- One data set, the survey questionnaire to members of the MDT, had to be excluded in the data gathering of this study due to a number of logistical challenges that have been met along the way. This may have influenced the richness of data that was gathered for this study.
- This study only included ambulatory stroke survivors who were able to communicate verbally. This study is, therefore, not representative of the broader stroke survivor population.

6.5. VALUE OF THIS STUDY

In view of the focus that is currently placed on PHC as well as the re-engineering of PHC services within SA (cf. 2.2.3.), this study has brought valuable insights forward regarding the roles (and exclusion thereof) of occupational therapy to stroke survivors, as well as the challenges that stroke survivors are experiencing when seeking to attend occupational therapy sessions within the PHC setting. Due to the rigor of this study and the consistent application of triangulation, these findings are trustworthy and, therefore, it has value for future investigation and implementation. This study has proven its significance by adding to the current body of knowledge for occupational therapy service delivery to stroke survivors, specifically within the PHC setting in the TMHD.

This study has also brought forward valuable insights into the future implementation of NHI, where the heartbeat of NHI is PHC, to make health care services accessible to all

people of SA (cf. 1.1., 2.2.5.). This study can offer valuable contributions toward the design of an occupational therapy (and rehabilitation) service package for stroke survivors within the NHI framework, as it provides valuable information and insight in addressing the challenges that are currently faced within PHC on grass root level. Although allied health services are not yet included in the vision for PHC within NHI, the results of this study may be used as evidence to advocate for the inclusion of occupational therapy and other allied health services.

This study does not only offer insights into the managerial aspects of the rendering of occupational therapy services, but valuable insights into the lives and experiences of stroke survivors have also been brought forward. This study offers an opportunity to design a service that will be relevant in meeting the needs of stroke survivors in a holistic manner.

This study has also highlighted the imperative role that the occupational therapist has to play within the PHC setting, especially in providing rehabilitation services to stroke survivors. This study encourages occupational therapists to be advocates for both the stroke survivor as well as for the rendering of occupational therapy services within the PHC setting.

6.6. CONTRIBUTION TO DESIGN KNOWLEDGE

As mentioned in chapters 1 and 3 (cf. 1.7., 3.3., 3.4.), this study has made use of DSR and only phase 1 has been executed. When this study commenced, no information, to the knowledge of the researcher, was available on the DSR methodology and the design of practice programs within occupational therapy. Although this posed some challenges, it was a fruitful experience to use DSR. During phase 1 of the DSR methodology, the most important aspect was to establish the relevance of the topic under study. Relevance on the topic of occupational therapy services to stroke survivors within the PHC setting was determined by making use of a mixed methodology.

Firstly, the problem within the context of the study was identified and described. Secondly, the researcher employed the use of a literature review that included a

document review, structural observations as well as expert interviews with a number of stakeholders. Lastly, the information that was gathered from the different data sets was synthesized in order to establish the relevance of the product that will be designed during phase 2 of the DSR process. Phase 1 provides the foundation from which the product will be designed and, therefore, the value of conducting thorough work in phase 1, cannot be over-emphasized.

The DSR process (all phases) can be positively utilized in the future development of occupational therapy practices, as it provides researchers with rich, contextual data that is scientifically sound and trustworthy. The DSR process and the use of a mixed methodology offer ample opportunities for occupational therapy practitioners to design products and programs that are implementable, based on scientific evidence and additionally contributes to future design knowledge.

6.7. OVERALL CONCLUSION

This study has reached the aim that was set in Chapter 1 namely, to identify the factors that will influence the relevance and feasibility in the design of an occupational therapy orientated intervention program for stroke patients within a rural PHC setting in the TMHD. With the identification and synthesis of these factors, implications for practice and recommendations for future research were made, specifically with the aim to designing an occupational therapy group program for stroke survivors within the PHC setting.

However, this study has also brought forward valuable insights to the researcher, over and above the objectives that were set. This study has opened the eyes of the researcher to an understanding of the real-life experiences of stroke survivors and their families that are often missed within the therapy process. Above all of the challenges that are experienced by therapists, this study has reiterated the importance of also attending to the challenges and experiences of the stroke survivors, keeping the client central within the delivery of services.

The important role that the occupational therapist has to play within PHC and in the delivery of services to stroke survivors, has been emphasized. The researcher firmly believes that this study has the potential to bring about change within the PHC setting if the recommendations for future research are followed and if an occupational therapy group program for stroke survivors is designed for the PHC setting.

The goals for rehabilitation services (including occupational therapy) within the PHC setting, as set within ***The Primary Health Care Package for South Africa – a set of norms and standards*** (Department of Health 2000, 67; emphasis added), read as follows:

Rehabilitation services are an integral part of the services provided at the primary level. This constitutes a reorientation of rehabilitation from mainly institution-based services to community oriented and community based services. Communities and particularly people with disabilities should be involved in designing, implementing and monitoring services for people with disabilities.
(Department of Health 2000, 67; emphasis added)

This study is undoubtedly a step towards reaching the goal for an integrated rehabilitation service within the PHC setting in the TMHD. This study aimed to contribute to the re-engineering of the occupational therapy service within PHC as well as to create a multidisciplinary and intersectoral approach where all stakeholders are included and acknowledged, fitting the ethos of PHC. The possibility of a future occupational therapy group program for stroke survivors, which will be presented in the community of the stroke survivor, keeps the dream of an accessible PHC service alive.

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ANNEXURES

ANNEXURE A: APPROVAL LETTER - HEALTH SCIENCES RESEARCH ETHICS COMMITTEE UFS



IRB nr 00006240
REC Reference nr Z30408-011
IDRG0005187
PWA00012784

26 July 2017

MS CEJ NAUDÉ
DEPT OF OCCUPATIONAL THERAPY
FACULTY OF HEALTH SCIENCES
UFS

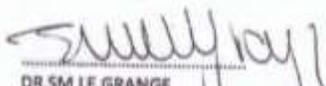
Dear Ms Naudé

HSREC 41/2017 (UFS-HSD2017/0304)
PRINCIPAL INVESTIGATOR: MISS CATHERINA EJ NAUDÉ
SUPERVISOR: ELIZE JANSE VAN RENSBURG, DEPT OF OCCUPATIONAL THERAPY
PROJECT TITLE: FACTORS INFLUENCING THE DESIGN OF AN OCCUPATIONAL THERAPY STROKE PROGRAM IN PRIMARY HEALTH CARE.

APPROVED

1. You are hereby kindly informed that the Health Sciences Research Ethics Committee (HSREC) approved this protocol after all conditions were met at the meeting held on 25 July 2017.
2. The Committee must be informed of any serious adverse event and/or termination of the study.
3. Any amendment, extension or other modifications to the protocol must be submitted to the HSREC for approval.
4. A progress report should be submitted within one year of approval and annually for long term studies.
5. A final report should be submitted at the completion of the study.
6. Kindly use the HSREC NR as reference in correspondence to the HSREC Secretariat.
7. The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act, No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

Yours faithfully



DR SM LE GRANGE
CHAIR: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE

Health Sciences Research Ethics Committee
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ANNEXURE B - APPROVAL LETTER - FREE STATE DEPARTMENT OF HEALTH RESEARCH ETHICS COMMITTEE



health

Department of
Health
FREE STATE PROVINCE

01 June 2017

Ms. CEJ Naude
Dept. of Occupational Therapy
Faculty of Health Sciences
UTS

Dear Ms. CEJ Naude

Subject: Factors influencing the design of an Occupational Therapy stroke program in Primary Health Care.

- Please ensure that you read the whole document, Permission is hereby granted for the above-mentioned research on the following conditions:
- Participation in the study must be voluntary.
- A written consent by each participants must be obtained
- Serious adverse events to be reported and/or termination of the study.
- Ascertain that your data collection exercise neither interferes with the day to day running of facilities nor the performance of duties by the respondents or health care workers.
- Confidentiality of information will be ensured and please do not obtain information regarding the identity of the participants.
- Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard copy plus a soft copy).
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of University of Free State and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee of University of Free State and to Free State Department of Health.
- Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Clearance Certificate should be submitted to ethics@fshs.gov.za before you commence with the study
- No financial liability will be placed on the Free State Department of Health
- Please discuss your study with the institution managers/CEOs on commencement for logistical arrangements
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- You are encouraged to present your study findings/results at the Free State Provincial health research day
- Future research will only be granted permission if correct procedures are followed see <http://ethics.fst.org.za>

Trust you find the above in order.

Kind regards

Dr D Motau
HEAD: HEALTH
Date: 02/06/17

Head : Health
PO Box 207, Stormbain, 8300
4th Floor, Executive Suite, Stephen's House, on Midland and Harvey Road, Bloemfontein
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ANNEXURE C - DATA EXTRACTION TABLE

Information Needed	Information Found										
	Free State Department of Health Strategic Plan 2015/16 - 2019/20	Free State Department of Health Annual Report 2015/2016	Free State Thabo Mofutsanya na District	Thabo Mofutsanya na Service Transformation Plan	Free State Department of Health Rehabilitation Policy Guidelines	Occupational Therapy policy DRAFT	District Health Plan 2016/2017	PHC package of SA 2000	Community Operation Manual 2006	Framework and Strategy for Disability and Rehabilitation Services in SA 2015-2020	National Rehabilitation Policy
Structural factors regarding the relevance of the current regulatory documents											
Re-engineering of PHC within the TMHD	<p>The district office ensures that PHC services are improved through PHC Re-engineering(Department of Health 2015b, p.22)</p> <p>Increase the number of Ward Based Outreach Teams by 2020 (Department of Health 2015b, p.36)</p>			<p>PHC to be the fundamental approach to provide health service delivery in the district (Free State Department of Health 2014, p.6)</p> <p>Implement the District Health System(Free State Department of Health 2014, p.6)</p> <p>Establish a Ward based community health profile plan (Free State Department of Health 2014, p.15)</p>							

				Establish multi-disciplinary outreach teams to do home visits (Free State Department of Health 2014, p.15)							
Financial support available for PHC services within the TMHD							Poor financial support for Rehabilitation services within the TMDH (Free State Department of Health 2015a, p.73)				Most provinces have limited budgets, if any, available for rehabilitation (Department of Health 2000a, p.4)
Role of OT within the Re-engineering of PHC services within the TMHD			No information on OT services	No information on OT services							
OT services integrated into operational plans of PHC facilities		Rehabilitation services are reflected as a strategic goal to improve access, but it only focuses on Orthotic and Prosthetic Services.(Free State Department		No mention is made of the OT as part of clinic services or as part of the outreach team that visits the clinics (Free State Department of Health 2014, pp.55, 56)		Policy states that a Primary Health care package must be developed to promote an integrated PHC Service but no such is available (Free State		OT only mentioned as part of Clinic Specialist team for Mental Health (Department of Health 2000b, p.54) Discuss rehabilitation services a		The implementation of rehabilitation services has no scope for integration with priority programs (Department of Health 2015a, p.8) Poor coordination	

		of Health 2016a, p.86)				Department of Health 2013, p.8)		whole and does not separate the different professions (Department of Health 2000b, pp.67-70)		of services between service levels (Department of Health 2015a, p.8) No indicators are available for rehabilitatio n outcomes within PHC (Department of Health 2015a, p.8)	
Role of OT within the proposed NHI enrollment plan											
Structural factors regarding the physical environment											
Equipment requireme nts to deliver OT services to PHC facilities										Portable: Assessment kit, Treatment kit, Treatment mat, Infection control kit, walking aids Clinic: Stainless steel bowl, Desk, two chairs.(Beuk es et al. 2006) Area must have at least one	

									power point (Occupational Therapy Component, Department of Health 2008)		
Accessibility requirements to deliver OT services at PHC facilities									The area at the clinic but be accessible for people with disabilities: <ul style="list-style-type: none"> • Non slip floors • Well lit areas • (Occupational Therapy Component, Department of Health 2008) 		
Provision made for physical space for OT services at PHC clinics									A private space must be available for treatment and can be shared by more than one therapist (Beukes et al. 2006) Adequate space must be available at the clinic on the day of outreach (Occupation		

									al Therapy Component, Department of Health 2008)		
Procedural factors regarding the involvement of the OT as part of the MDT team when the rendering of stroke services within the PHC setting											
OT is mentioned as one of the key services to be provided at a PHC Clinic			No mention is made of the OT as part of clinic services or as part of the outreach team that visits the clinics (Free State Department of Health 2014, pp.55, 56)		OT indicated as a member of the ideal care rehab team (Free State Department of Health n.d., p.12)				Discuss rehabilitation services a whole and does not separate the different professions (Department of Health 2000b, pp.67–70)		The ideal core rehabilitation team should include an OT (Department of Health 2015a, p.8)
Occupational Therapist indicated as a core role player within the rehabilitation team					OT indicated as a member of the ideal care rehab team (Free State Department of Health n.d., p.12)						The ideal core rehabilitation team should include an OT (Department of Health 2015a, p.8)
Referral guideline available to refer stroke patients to OT within PHC									Referral is discussed in general and does not indicate the referral process to the different rehabilitation officials.		Poor referral pathways for rehabilitation services exist (Department of Health 2015a, p.8)
Training for the MDT team											

on the roles of different team members											
Procedural factors essential in ensuring the OT intervention is relevant and feasible											
Human Resources available for OT services within TMHD		23.1% vacancy rate of Occupational Therapists within FSDoH (Free State Department of Health 2016a, p.139)									Rehabilitation personnel should form part of the PHC Team (Department of Health 2000a, p.13)
Human Resource Plan for OT within PHC		Only focuses on strengthening human resource for Orthotic and Prosthetic services (Free State Department of Health 2016a, p.86)								High vacancy rate of rehabilitation officials at primary level (Department of Health 2015a, p.9)	
Financial support available for OT within PHC in the TMHD											
Objectives for OT service delivery within PHC										OT help people gain independence in all areas of their lives. OT can help	

										with the treatment of neuropsychological deficits, motor function, sensory function and interpersonal skills. (Department of Health 2015a, p.19)	
Therapy program guidelines for OT intervention for stroke patients											
Issuing of assistive devices to stroke patients											
Monitoring and evaluation strategies available for OT services within PHC						One of the objectives of the policy is to provide guidelines on monitoring and evaluation strategies - but no guidelines are stated (Free State Department of Health 2013, p.5)					

<p>Challenges faced by occupational therapists within PHC</p>										<p>Rehabilitation personnel face a range of challenges:</p> <ul style="list-style-type: none"> • Use of medical model • Poor referral pathways • Inadequate follow-up of patients • Inaccessible health care services • Inadequate provisioning of assistive devices • Lack of awareness and knowledge on the challenges people with disabilities face • Unavailability of rehabilitation indicators • Ideal core rehabilitation team does not 	
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										exist (Department of Health 2015a, p.8)	
Challenges stroke patients experience when making use of OT services within the PHC setting											
Challenges faced by stroke patients within PHC										<ul style="list-style-type: none"> • Inaccessible and unaffordable transport • Therapy is not provided in the client's first language • Poor cultural sensitivity (Department of Health 2015a, p.8) 	•
Transport arrangements for patients making use of PHC services										Inaccessible and unaffordable transport (Department of Health 2015a, p.8)	

ANNEXURE D - STRUCTURED OBSERVATIONS CHECKLIST AT PRIMARY HEALTH CARE CLINICS

Structural Observation Checklist for Primary Health Care Clinics

Name of PHC Clinic:	
Date Assessed:	
Name of Assessor:	

	Standard	Yes/No	Comment
	There is an appropriate and accessible entrance to the clinic:		
1	There are curb cuts, ramps (at appropriate gradient of 1:12) OR level entrance.		
2	All curbs (where applicable) have curb cuts and ramps are provided if height of curbs exceed 15mm OR entrance is level.		
3	Ramp gradient of 1:12 (degree of slope of 4.80) with width at least 1100mm OR level entrance.		
4	There is a passenger drop off zone adjacent to the accessible entrance.		
	The space inside the clinic is accessible to people with disabilities:		
5	Passages and thoroughfares in waiting area are wide enough for passage of wheelchairs even when busy.		
6	Step or stair tread noses in contrasting colour/texture to floor or staircase/step covering OR even floor levels throughout facility.		
7	Floor surfaces are not slippery (even if wet).		
8	Lights in all staircases and/or passages are in a working condition.		
	There is an appropriate and accessible bathroom for people with disabilities:		
9	At least one unisex toilet designated for people with		

	disabilities in the public area.		
10	Larger toilet cubicle size with outward opening door (>1500mm X 1500mm clear space for wheelchair to turn).		
11	Centre of toilet pan situated a maximum of 500mm from nearest wall.		
12	At least two support rails (horizontal and cranked), on rear and nearside walls.		
13	All handrails are not higher than 800mm from floor level.		
14	An internal locking device with external emergency override facility.		
15	Light switch less than 1200mm above floor level.		
16	Toilet seat 460-480mm above floor level.		
17	Extended and accessible lever-type flush controls.		
18	A hand wash basin in the toilet cubicle or just outside with clear space under the basin of 650mm.		
19	Hand drying facilities accessible from a wheelchair in the toilet cubicle or just outside.		
20	Emergency call device at/or near the toilet.		
	There is a therapy space available for OT treatment		
21	There is a private space available for OT individual treatment - a separate room with a closing door.		
23	Size of Available treatment area at least 36m ² (measure length x with).		
22	There is an open space available for OT group therapy (indicate size of space).		
24	The space available has at least one power point.		
25	The space available has chairs for patients to sit on.		
26	The space available has a table/tables.		
27	The space available has a basin with running water.		
	There is adequate and relevant equipment and materials to provide an effective service. The following equipment is available at the clinic:		
28	NDT-plinth		
29	Radio		

30	Mirror		
31	Other		

ANNEXURE E - INFORMATION DOCUMENT FOR STRUCTURED INTERVIEWS WITH COMMUNITY HEALTH CARE WORKERS

To whom it may concern

REQUEST TO CONDUCT RESEARCH AT (name of clinic) CLINIC

I, Liezel Naudé, have been granted permission to conduct a research study within the Thabo Mofutsanayana Health District by the HOD of the Department (approval letter attached). The study will be in fulfillment of the requirements for a Master's Degree in occupational Therapy from the University of the Free State. The study will focus on Primary Health Care and stroke patients.

As part of the research, I have to do an accessibility checklist for a Primary Health Care Clinic. I am hereby requesting permission to do an accessibility assessment at your clinic. The assessment will take approximately 15 minutes to complete and will not disrupt any of the clinic's activities. The assessment will be conducted on 10 August 2017.

Should you require any additional information or should you have any comments, please do not hesitate to contact me.

Thank you in advance for your assistance and support in this matter. Your effort, time and positive attitude is highly appreciated!

The Researcher

Liezel Naudé (B.OT UFS)

072 606 3058

DATE

ANNEXURE F - STRUCTURED INTERVIEW SCHEDULE

Structured Interview Schedule for Community Health Workers

Demographic Information

1. **What is your age?** O dilemo di kae?

_____Years

2. **What is your gender?** O motona kapa o motshehadi?

Male Motona

Female Motshehadi

3. **Who is your employer?** O hirilwe kae hajwale?

4. **To which patient populations are you providing services?** O fana ka ditshebeletso ho ditjhaba dife tsa bakudi?

5. **How many years' experience do you have as a COMMUNITY HEALTH WORKER in the TAHBO MOFUTSANYANA HEALTH DISTRICT?** O na le boiphihllo ba dilemo tse kae jwaloka COMMUNITY HEALTH WORKER ho TAHBO MOFUTSANYANA HEALTH DISTRICT?

6. **How many years' experience do you have in working with stroke patients?** O na le boiphihllo ba dilemo tse kae ho sebetseng le bakudi ba seterouku?

Structural factors regarding the relevance of the current regulatory documents

7. **What policies or protocols are you using to guide your day-to-day functioning as a Community Health Worker?** Ke ditokomane dife tsa semmuso tse o di sebedisang ho tataisa tshebetso ya hao ya letsatsi ka leng jwaloka COMMUNITY HEALTH WORKER?
-

Structural factors regarding the physical environment

8. **Where do you provide services to stroke patients?** O fana ka ditshebeletso kae ho bakudi ba seterouku?

PHC Clinic Tleliniking ya PHC

Patient's home Lapeng la mokudi

Other, please specify: E nngwe, hlalosa ka kopo:

Procedural factors regarding the involvement of the OT as part of the MDT team when the rendering of stroke services within the PHC setting

9. **Which rehabilitation officials are available to assist you with stroke patients?**
-

10. **Do you know how to refer a patient to an occupational therapist?** Na o tseba ho fetisetsa mokudi ho OT?

Yes Ee

No Tjhe

Comments: Maikutlo: _____

11. **How often do you refer stroke patients to Occupational Therapy?**
-

12. Do you know what services the occupational therapist can offer to stroke patients? Na o tseba ditshebeletso tseo OT e ka fanang ka tsona ho bakudi ba seterouku?

Yes Ee

No Tjhe

Comments: Maikutlo: _____

Challenges stroke patients experience when making use of OT services within the PHC setting

13. Out of your experience, what would you say are the biggest challenges stroke patients face within the community? Ka boiphihlelo ba hao, o ka re mathata a maholo ho fetisisa ao bakudi ba seterouku ba kopanang le ona setjhabeng ke afe?

14. Which of the following makes access to rehabilitation services difficult for stroke patients? You can choose more than one. Ke efe ya tse latelang e thatafatsang phihlelo ho ditshebeletso tsa tlhabollo bakeng sa bakudi ba seterouku?

Limited knowledge of the benefits of therapy Tsebo e fokolang ka melemo ya kalafo

High transportation costs Ditefiso tse phahameng tsa dipalangwang

Clinic/hospital too far from patient's home Tleliniki/sepetelele se hole haholo ho lehae la mokudi

Poor family support system Tshehetso e fokolang ho tswa ho lelapa

Patient does not have a suitable assistive device or wheelchair to allow him/her to access the clinic Mokudi ha a na sesebediswa se loketseng ho mo thusa ho fihla tleliniking

Clinic does not offer adequate space for rehabilitation services

Tleliniki/sepetelele ha se fane ka sebaka se loketseng bakeng sa ditshebeletso tsa tlhabollo

Other, please specify: E nngwe, hlalosa ka kopo:

15. **Please indicate which of the following aspects you regard as important when occupational therapy services are rendered to stroke patients (you can choose more than 1 answer):** Ka kopo hlalosa hore na ke dintlha dife ho tse latelang tseo o nkang di le bohlokwa ha ditshebeletso tsa OT di fanwa ho bakudi ba seterouku (o ka kgetha karabo tse fetang e le nngwe):

Functional mobility (being able to move around with or without a walking aid)

Motsamao wa tshebetso (ho kgona ho tsamatsamaya ka kapa ntle le sesebediswa sa thuso ya ho tsamaya)

Cognitive functioning (includes reasoning, memory, attention and language)

Tshebetso ya tlhalohanyo (e kenyetsa ho fana ka mabaka, kgopolo, tsepamiso le puo)

Affective components (the feelings and emotions of the patient) Dintlha tsa kameho (maikutlo le mehopolo ya mokudi)

Motivational Components (the willingness to participate in activities) Dintlha tsa kgothatso (takatso ya ho nka karolo ditshebetsong)

Activities of daily living (daily routine activities such as bathing, dressing and toileting) Mesebetsi ya bophelo ba letsatsi ka leng (mesebetsi ya kamehla e jwaloka ho hlapa, ho apara le ho ya ntlwaneng)

Recreation (leisure activities) Boithapollo (mesebetsi ya boithapollo)

Vocational re-integration (integrating the patient into a work environment after the stroke) Tlwaetso-botjha ya mesebetsi (ho kenyetsa mokudi tikolohong ya mesebetsi kamora ho ba le seterouku)

Community re-integration (integrating the patient back into the community after the stroke such as going to church or watching a local soccer match)

Tlwaetso-botjha ya setjhaba (ho kenyeletsa mokudi setjhabeng hape kamora ho ba le seterouku jwaloka ho ya kerekeng kapa ho boha papadi ya bolo ya lehae)

Adequate family involvement (involving the family in decision making and execution of home programs) Ho nka karolo ho lekaneng hwa lelapa (ho kenyeletsa lelapa ho etsweng ha diqeto le ho ketso ya mananeo a lelapa)

Appropriate cultural sensitivity Tlhokomelo e loketseng ya setso

None of the above Ha e yo ho tse kahodimo

If other, please specify: Haeba ke e nngwe, hlalosa ka kopo:

16. If a structured program was available to provide rehabilitation services to the stroke patient in the community, would you be willing to present such a program if you receive training? Haeba lenaneo le hlophisitsweng le ne le fumanaha ho fana ka ditshebeletso tsa tlabollo ho mokudi wa seterouku setjhabeng, na o ne o ka ikemisetsa ho nehelana ka lenaneo le jwalo haeba o fuwe thupello?

Yes Ee

No Tjhe

17. Would you prefer to provide such a program to stroke patients individually or within a group? Na o ka thabela ho nehelana ka lenaneo le jwalo ho bakudi ba seterouku ka bonngwe kapa ka sehlopha?

Individual Ka bonngwe

Group Sehlopha

Both

18. Please motivate your answer in question 15. Fana ka mabaka bakeng sa karabo ya hao.

19. If stroke rehabilitation programs would be presented in groups: According to your experience, where would be the ideal venue to present such a group? Haeba mananeo a tlabollo ya seterouku a ne a ka fanwa ka dihlopha: Ho latela

boiphihlello ba hao, sebaka se loketseng sa ho kopana le sehlopha seo e ka ba sefe?

PHC Clinic Tleliniki ya PHC

Community Hall Holo ya Setjhaba

Closest Hospital Sepetlele se haufi

Other, please specify: Se seng, hlalosa ka kopo:

ANNEXURE G - INFORMATION DOCUMENT FOR STRUCTURED INTERVIEWS WITH COMMUNITY HEALTH CARE WORKERS

INFORMATION DOCUMENT

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

Dear Community Health Worker

I, Liezel Naudé, am doing research on the factors that will influence the designing of an Occupational Therapy program that can be used for the treatment of stroke patients within a rural Primary Health Care setting in the Thabo-Mofutsanyana Health District. Research is just the process to learn the answer to a question and in this study I want to learn what factors will influence the relevance and feasibility of an occupational therapy orientated intervention program for stroke patients by conducting research amongst community health care workers. The aim of this study is to compile a document with factors that will influence and guide the researcher in designing an occupational therapy program for stroke patients in the future. The study originates from the renewed focus that is placed on the Re-engineering of primary health care services across South Africa as well as internationally. This study therefore seeks to address the current challenges that are faced when rendering occupational therapy services to stroke patients within a rural Primary Health Care setting.

Invitation to participate:

You are hereby kindly invited to participate in the study. Participation in the study is voluntary and refusal to participate will involve no loss or penalty of benefits to which you are entitled. You may withdraw from participation at any time without loss of benefits. Your complete honesty is required when answering questions, to ensure the legitimacy of the results.

What is involved in the study:

A design science research methodology will be used. As part of the study process, all participants will be requested to participate in a one on one structured interview. The interview will take approximately 30 minutes to complete. The interview will be done by the researcher in English and a translator will be available to translate the questions to Sesotho and Afrikaans.

Risks and benefits of participating in the study:

There are no physical risks involved in the study and no costs will be payable to participants. Benefits of participating in the study include assisting the researcher in identifying and describing the factors that will influence the designing of an Occupational

Therapy orientated intervention for stroke patients. Please take note that the results of this study may be published after completion of the study.

Ethical aspects and confidentiality:

Approval has been obtained from The Health Sciences Research Ethics Committee of the University of the Free State. Personal information will be kept confidential at all times and information shared will not at any time be associated with an individual.

Contact details of researcher:

Should you require any further information, please contact the researcher on 0726063058 or send an email to liezel.naude22@gmail.com.

For queries on your rights as a participant, problems or complaints, you can contact the Secretariat and Chair of the Health Sciences Research Ethics Committee of the University of the Free State at (051) 405 2812.

Thank you in advance for being willing to participate in the above mentioned study.

INLIGTINGSDOKUMENT

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

Beste Gemeenskap Gesondheidswerker

Ek, Liezel Naudé, is tans besig om navorsing te doen oor die faktore wat die ontwerp van 'n Arbeidsterapie program vir beroerte pasiënte, binne 'n landelike primêre gesondheidsorgomgewing binne die Thabo-Mofutsanyana Gesondheidstreek, sal beïnvloed. Navorsing is egter slegs die proses wat gebruik word om 'n vraag te beantwoord en in hierdie studie wil ek die verskillende faktore navors wat die belang en uitvoerbaarheid van 'n arbeidsterapie geïntegreerde benadelingsprogram vir beroerte pasiënte sal beïnvloed. Ek poog om die navorsing uit te voer deur die hulp van gemeenskap gesondheidswerkers. Die doel van hierdie studie is om 'n dokument saam te stel met die faktore wat die ontwerp van 'n arbeidsterapie program vir beroerte pasiënte sal rig in die toekoms. Hierdie studie het ontstaan vanuit die hernude fokus wat geplaas word op herstrukturering van die primêre gesondheidstelsel in Suid-Afrika asook internasionaal. Hierdie studie het dus ten doel om die huidige uitdagings aan te spreek wanneer arbeidsterapie dienste aan beroerte pasiënte gelewer word in 'n landelike primêre gesondheidsorg omgewing.

Uitnodiging tot deelname:

U word vriendelik uitgenooi om deel te neem aan hierdie studie. Deelname aan die studie is vrywillig en weiering om aan die studie deel te neem hou geen verliese of straf tot voordele waarop u geregtig is, in nie. U mag enige tyd van die studie onttrek sonder verlies van voordele. U absolute eerlikheid is noodsaaklik wanneer u die vrae beantwoord, om sodoende geldigheid van die resultate te verseker.

Wat die studie behels:

Die navorser gaan 'n wetenskaplike ontwerp navorsingsmetodologie gebruik in die uitvoering van die navorsing. As deel van die navorsingsproses sal deelnemers gevra word om aan 'n een-tot-een gestruktureerde onderhoud deel te neem. Die onderhoud sal ongeveer 30 minute neem en dit sal deur die navorser in Engels aangebied word. Daar sal 'n tolk beskikbaar wees om die vrae na Sesotho en Afrikaans te vertaal.

Risiko's en voordele van deelname aan die studie:

Die studie hou geen fisiese gevare vir gesondheidswerkers in nie en geen vergoeding sal aan deelnemers betaal word nie. Die voordele van deelname aan die studie sluit in dat u die navorser bystaan om die faktore te identifiseer en te beskryf wat die ontwerp van 'n arbeidsterapie geïntegreerde benadering vir beroerte pasiënte, sal beïnvloed. Neem asseblief kennis dat die resultate van die studie moontlik gepubliseer kan word na afloop van die studie.

Etiese aspekte en konfidensialiteit:

Goedkeuring is ontvang van die Gesondheids Wetenskappe Navorsings Etiekkomitee van die Universiteit van die Vrystaat. Persoonlike inligting sal te alle tye vertroulik gehou word en inligting wat ingesamel word sal in geen stadium aan 'n individu gekoppel word nie.

Kontakbesonderhede van die navorser:

Indien u enige addisionele inligting benodig, kontak asseblief die navorser op 0726063058 of stuur 'n e-pos na liezel.naude22@gmail.com.

Vir enige navrae rakende u regte as 'n deelnemer, probleme of klagtes, kontak asseblief die Sekretariaat of Voorsitter van die Gesondheids Wetenskappe Navorsings Etiekkomitee van die Universiteit van die Vrystaat op (051) 405 2812.

Byvoorbaat dank vir 'n deelname in die bogenoemde studie.

TOKOMANE YA TLHAHISOLESEDING

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

Mosebeletsi wa Setjhaba wa tsa Bophelo bo botle ya Kgabane

Nna, Liezel Naudé, ke etsa diphuputso mabapi le dintlha tse tla ama ho ralwa ha lenaneo la Kalafo ya Tshebetso le ka sebediswang bakeng sa kalafo ya bakudi ba seterouku maemong a Tlhokomelo ya Motheo ya Bophelo bo Botle ya mahaeng Seterekeng sa Bophelo bo Botle sa Thabo-Mofutsanyana. Phuputso ke feela tsela ya ho ithuta karabo ya potso mme phuputsong ena ke batla ho ithuta hore na ke dintlha dife tse tla ama ho hlokahala le menyetla ya katleho ya lenaneo la keno-dipakeng la Kalafo ya Tshebetso bakeng sa basebeletsi ba Setjhaba ba Bophelo bo Botle ba hirilweng ditlheliniking tsa Tlhokomelo ya Motheo ya Bophelo bo Botle seterekeng. Sepheo sa phuputso ena ke ho hlophisa tokomane e nang le dintlha tse tla susumetsa le ho tataisa mofuputsi ho raleng lenaneo la kalafo ya tshebetso bakeng sa bakudi ba seterouku kamoso. Phuputso e hlaha ho tsepamiso e ntjhafaditsweng e thehilweng hodima tekolo-botjha ya ditshebeletso tsa tlhokomelo ya motheo ya bophelo bo botjha Afrika Borwa ka bophara hammoho le matjhabeng. Kahoo, phuputso ena e batla ho sebetsana le diphepetso tsa hona jwale tseo ho shebanweng le tsona ha ho fanwa ka ditshebeletso tsa kalafo ya tshebetso ho bakudi ba seterouku boemong ba Tlhokomelo ya Motheo ya Bophelo bo Botle.

Memo ya ho nka karolo:

O mengwa ho nka karolo phuputsong. Bonkakarolo phuputsong ke ka boithaopo mme ho hana ho nka karolo ho ke ke ha baka tahlehelo kapa kotlo melemong eo o nang le tokelo ho yona. O ka ikgula bonkakarolong ka nako efe kapa efe ntle le tahlehelo ya melemo. Ho hlokahala botshepeho bo phethahetseng ha o araba dipotso, ho netefatsa bonnete ba diphetho.

Phuputso e kenyeletsa eng:

Ho tla sebediswa tsela ya patlisiso ya moralo wa saense. Jwaloka karolo ya tshebetso ya phuputso, bankakarolo bohle ba tla koptjwa ho nka karolo inthavuweng e hlophisitsweng ya motho ka bomong. Inthavu e tla nka metsotso e 30 ho e phethela. Inthavu e tla etswa ke mofuputsi mme ho tla ba le mofetoledi ho fetolela dipotso ho Sesotho le ho seAfrikaans.

Dikotsi le melemo ya ho nka karolo phuputsong:

Ha hona dikotsi tsa mmele tsa phuputso mme ha ho ditjeo tse tla lefuwa ho bankakarolo. Leha ho le jwalo, bankakarolo ba tla buseletswa tjelete bakeng sa ditshenyehelo tsa maeto a ho nka karolo phuputsong. Melemo ya ho nka karolo phuputsong e kenyeletsa ho thusa mofuputsi ho hlwaya le ho hlalosa dintlha tse tla susumetsa ho ralwa ha lenaneo la keno-dipakeng la Kalafo ya Tshebetso bakeng sa bakudi ba seterouku. Ka kopo lemoha hore diphetho tsa phuputso ena di kanna tsa hlahiswa kamora hore phuputso e fele.

Dintlha tsa boitshwaro le sephiri:

Tumello e fumanwe ho tswa ho Komiti ya Boitshwaro ya Diphuputso tsa Disaense tsa Bophelo bo botle ya Yunivesithi ya Foreisitata. Tlhahisoleseding ya motho e tla bolokwa e le sephiri ka dinako tsohle mme tlhahisoleseding e arolelanwang e ke ke ya amahangwa le motho ya itseng ka nako efe kapa efe. Tlhahisoleseding yohle e bokeletswang e tla tlotswa dintlha tsa boitsebiso.

Dintlha tsa boiteanyo tsa mofuputsi:

Ha o ka hloka tlhahisoleseding efe kapa efe e eketsehileng, ka kopo iteanye le mofuputsi ho 0726063058 kapa o mo romele imeile ho liezel.naude22@gmail.com.

Bakeng sa dipotso mabapi le ditokelo tsa hao jwaloka monkakarolo, mathata kapa ditlitlebo, o ka iteanya le Mongodi le Modulasetulo wa Komiti ya Boitshwaro ya Diphuputso tsa Disaense tsa Bophelo bo botle ya Yunivesithi ya Foreisitata ho (051) 405 2812.

Re leboha thahasello ya hao ya ho nka karolo phuputsong e boletsweng kahodimo.

ANNEXURE H - CONSENT FORM FOR COMMUNITY HEATH CARE WORKERS

CONSENT TO PARTICIPATE IN RESEARCH

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

You have been asked to participate in a research study. You have been informed about the study by the researcher, Me L Naudé.

You may contact Me L Naudé at 0726063058 any time if you have questions about the research or if you experience any discomfort as a result of the research.

You may also contact the Secretariat of the Health Sciences Research Ethics Committee of the University of the Free State at telephone number (051) 4052812 if you have questions about your rights as a research subject.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate.

Signature of Participant

Date

Signature of Witness

Date

Signature of Translator

Date

TOESTEMMING TOT DEELNAME AAN NAVORSING

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

U is versoek om aan 'n navorsingstudie deel te neem. U is deur die navorser, Mej. L Naudé, ingelig oor die studie.

U kan Mej. Naudé enige tyd kontak indien u enige vrae het oor die navorsing of as u enige ongemak ervaar het weens deelname aan die navorsing. Die kontaknommer: 0726063058.

U kan ook die Sekretariaat van die Gesondheids Wetenskappe Navorsings Etiekkomitee van die Universiteit van die Vrystaat skakel by kontaknommer (051) 405 2812 indien u enige navrae het oor u regte as 'n deelnemer aan die navorsing.

U deelname aan hierdie navorsing is vrywillig en u sal nie benadeel word of voordele verloor indien u weier om deel te neem of u deelname aan die studie staak nie.

Indien u toestemming gee tot deelname aan die studie, sal u 'n getekende afskrif van hierdie dokument ontvang asook die inligtingsdokument wat 'n opsomming van die navorsing bevat.

Hierdie navorsingstudie sowel as die inligting hierbo vervat, is verbaal aan my beskryf. Ek verstaan wat deelname aan die studie behels en ook dat ek vrywillig instem tot deelname aan die studie.

Handtekening van deelnemer

Datum

Handtekening van getuie

Datum

Handtekening van tolk

Datum

TUMELLO YA HO NKA KAROLO PHUPUTSONG

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

O kopilwe ho nka karolo phuputsong ya boithuto. O bolelletswe ka phuputso ke mofuputsi, Me L Naudé.

O ka iteanya le Me L Naudé ho 0726063058 ka nako efe kapa efe haeba o na le dipotso mabapi le phuputso kapa haeba o ba le makukuno afe kapa afe ka lebaka la phuputso.

O boetse o ka iteanya le Mongodi wa Komiti ya Boitshwaro ya Diphuputso tsa Disaense tsa Bophelo bo botle ya Yunivesithi ya Foreisitata nomorong ya mohala (051) 4052812 haeba o na le dipotso mabapi le ditokelo tsa hao jwaloka monkakarolo wa phuputso.

Bonkakarolo ba hao phuputsong ke ka boithapo, mme o ke ke wa fuwa kotlo kapa wa lahlehelwa ke melemo haeba o hana ho nka karolo kapa o nka qeto ya ho ikgula.

Haeba o dumela ho nka karolo, o tla fuwa khophi e tekennweng ya tokomane ena hammoho le leqephe la tlhahisoleseding ya monkakarolo, e leng kgutsufatso e ngotsweng ya phuputso.

Phuputso ya boithuto, hammoho le tlhahisoleseding e ka hodimo ke e hlaloseditswe ka molomo. Ke utlwisisa hore na bonkakarolo ba ka phuputsong bo bolelang mme ke dumela ka boithaopo ho nka karolo.

Tekeno ya Monkakarolo

Mohla

Tekeno ya Paki

Mohla

Tekeno ya Mofetoledi

Mohla

ANNEXURE I - INFORMATION DOCUMENT FOR PARTICIPATION IN FOCUS GROUP BY OCCUPATIONAL THERAPISTS

INFORMATION DOCUMENT

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

Dear Occupational Therapist

I, Liezel Naudé, am doing research on the factors that will influence the designing of an Occupational Therapy program that can be used for the treatment of stroke patients within a rural Primary Health Care setting in the Thabo-Mofutsanyana Health District. Research is just the process to learn the answer to a question and in this study I want to learn what factors will influence the relevance and feasibility of an occupational therapy orientated intervention program for stroke patients by conducting research amongst occupational therapists who are known to the Thabo-Mofutsanyana Health District. The aim of this study is to compile a document with factors that will influence and guide the researcher in designing an occupational therapy program for stroke patients in the future. The study originates from the renewed focus that is placed on the Re-engineering of primary health care services across South Africa as well as internationally. This study therefore seeks to address the current challenges that are faced when rendering occupational therapy services to stroke patients within a rural Primary Health Care setting.

Invitation to participate:

You are hereby kindly invited to participate in the study. Participation in the study is voluntary and refusal to participate will involve no loss or penalty of benefits to which you are entitled. You may withdraw from participation at any time without loss of benefits. Your complete honesty is required when answering questions, to ensure the legitimacy of the results.

What is involved in the study:

A design science research methodology will be used. As part of the study process, all participants will be requested to participate in a focus group. The focus group will take approximately 2 hours and will be presented to the participants in English. The focus group will be recorded and a facilitator will be presenting the group while the researcher will take notes. After the group, the recording will be downloaded to an external drive and will be stored in a safe and lockable area to ensure confidentiality. The recording will be transcribed for data analysis purposes.

Risks and benefits of participating in the study:

There are no physical risks involved in the study and no costs will be payable to participants. Benefits of participating in the study include assisting the researcher in identifying and describing the factors that will influence the designing of an Occupational Therapy orientated intervention for stroke patients. Please take note that the results of this study may be published after completion of the study.

Ethical aspects and confidentiality:

Approval has been obtained from The Health Sciences Research Ethics Committee of the University of the Free State. Personal information will be kept confidential at all times and information shared will not at any time be associated with an individual. All information gathered will be de-personalized.

Contact details of researcher:

Should you require any further information, please contact the researcher on 0726063058 or send an email to liezel.naude22@gmail.com.

For queries on your rights as a participant, problems or complaints, you can contact the Secretariat and Chair of the Health Sciences Research Ethics Committee of the University of the Free State at (051) 405 2812.

Thank you in advance for being willing to participate in the above mentioned study.

ANNEXURE J - CONSENT FORM FOR OCCUPATIONAL THERAPISTS

CONSENT TO PARTICIPATE IN RESEARCH

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

You have been asked to participate in a research study. You have been informed about the study by the researcher, Me L Naudé.

You may contact Me L Naudé at 0726063058 any time if you have questions about the research or if you experience any discomfort as a result of the research.

You may also contact the Secretariat of the Health Sciences Research Ethics Committee of the University of the Free State at telephone number (051) 4052812 if you have questions about your rights as a research subject.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate.

Signature of Participant

Date

Signature of Witness

Date

ANNEXURE K - FOCUS GROUP SCHEDULE

Interview schedule for Occupational Therapists

1. How do you see your role as an occupational therapist in the management of your stroke clients?

2. The question can be related to following aspects:

- a. Structural factors (Financial support, policies and procedures as well as the physical environment)
- b. Procedural factors (Current OT intervention, challenges experienced, adaptations that would make OT services more feasible and relevant)
- c. Challenges stroke patients experience (Occupational Therapists view on the challenges stroke patients experience)
- d. What changes would you make to the current model of rendering OT services to stroke patients, in order to foster positive change and make OT services more accessible to stroke patients within the PHC setting in the TMHD

ANNEXURE L - SEMI STRUCTURED INTERVIEW SCHEDULE WITH STROKE SURVIVORS

Semi- Structured Interview schedule with stroke survivors

Demographic Information

- 1. What is your age?**
- 2. What is your gender?**
- 3. When were you diagnosed with a stroke? (Who)**
- 4. Do you know what a stroke is? (What caused your stroke)**

Structural factors regarding the physical environment
--

- 5. Have you received Occupational Therapy after being diagnosed with a stroke?**
- 6. Where did you attend occupational therapy - your local clinic or hospital?**
- 7. Was it easy to go to travel to the hospital/clinic to attend therapy?**
- 8. How far do you have to travel to the clinic/hospital? (What makes it difficult)**
- 9. How do you travel to the clinic/hospital? (Private vehicle, taxi, ambulance)**
- 10. How much money do you have to pay the taxi/ambulance to take you to the hospital?**

Procedural factors regarding the involvement of the OT as part of the MDT team when the rendering of stroke services within the PHC setting

11. After being diagnosed with a stroke, what services did you receive? (Which health care providers have you consulted?)

- 11.1. Occupational Therapy**
- 11.2. Physiotherapy**
- 11.3. Speech Therapy**
- 11.4. Audiology Services**
- 11.5. Consultation from a Medical Officer**
- 11.6. Consultation from a Registered Nurse**
- 11.7. None**
- 11.8. Other**

12. Who referred/send you to occupational therapy?

Procedural factors essential in ensuring the OT intervention is relevant and feasible

13. For how long have you received occupational therapy sessions?

14. How regular do you attend occupational therapy sessions? (Would you want to attend more OT sessions, what is preventing you from doing so?)

15. What is the average duration of your occupational therapy sessions? (Do you think it is long enough?)

16. What did you struggle (problems) with after the stroke? (Body function, Sleep, Work, Leisure, Washing, Eating, Dressing, social participation) (How has your life changes after the stroke?)

17. Did the Occupational Therapy sessions help to overcome the problems after the stroke?

18. What would you want to be added to your Occupational Therapy sessions? (in order to be more independent)

19. Was your family involved enough in the Occupational Therapy session? (Was this helpful? Should they have been involved more?)

20. What in your life has changed after the stroke, compared to before the stroke? (Individual, community participation)

Challenges stroke patients experience when making use of OT services within the PHC setting
--

21. What makes coming to Occupational Therapy sessions difficult? (describe, explain)

22. If an Occupational Therapist is available at your closest clinic, would you prefer to receive therapy there?

23. Please motivate your answer in the previous question.

24. Would you join a group for people who had strokes? (Yes, why? ; what would you want to do in the group?)

ANNEXURE M - INFORMATION DOCUMENT FOR PARTICIPATION IN SEMI STRUCTURED INTERVIEWS BY STROKE SURVIVORS

INFORMATION DOCUMENT

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

Dear Patient

I, Liezel Naudé, am doing research on the factors that will influence the designing of an Occupational Therapy program that can be used for the treatment of stroke patients within a rural Primary Health Care setting in the Thabo-Mofutsanyana Health District. Research is just the process to learn the answer to a question and in this study I want to learn what factors will influence the relevance and feasibility of an occupational therapy orientated intervention program for stroke patients by conducting research amongst stroke patients who are known to occupational therapy services on a District level. The aim of this study is to compile a document with factors that will influence and guide the researcher in designing an occupational therapy program for stroke patients in the future. The study originates from the renewed focus that is placed on the Re-engineering of primary health care services across South Africa as well as internationally. This study therefore seeks to address the current challenges that are faced when rendering occupational therapy services to stroke patients within a rural Primary Health Care setting.

Invitation to participate:

You are hereby kindly invited to participate in the study. Participation in the study is voluntary and refusal to participate will involve no loss or penalty of benefits to which you are entitled. You may withdraw from participation at any time without loss of benefits. Your complete honesty is required when answering questions, to ensure the legitimacy of the results.

What is involved in the study:

A design science research methodology will be used. As part of the study process, all participants will be requested to participate in a one-on-one semi-structured interview with the researcher. Questions will be presented in Afrikaans, English and/or Sotho. A translator will be available and the interview will take approximately one hour to complete. The interview will be recorded and the researcher will also take notes during the interview. After the interview, the recording will be downloaded to an external drive and will be stored in a safe and lockable area to ensure confidentiality. The recording will also be transcribed for data analysis purposes.

Risks and benefits of participating in the study:

There are no physical risks involved in the study and no costs will be payable to participants. Participants will however be reimbursed for travel expenses to participate in the research. Benefits of participating in the study include assisting the researcher in identifying and describing the factors that will influence the designing of an Occupational Therapy orientated intervention for stroke patients. Please take note that the results of this study may be published after completion of the study.

Ethical aspects and confidentiality:

Approval has been obtained from Health Sciences Research Ethics Committee of the University of the Free State. Personal information will be kept confidential at all times and information shared will not at any time be associated with an individual. All information gathered will be de-personalized.

Contact details of researcher:

Should you require any further information, please contact the researcher on 0726063058 or send an email to liezel.naude22@gmail.com.

For queries on your rights as a participant, problems or complaints, you can contact the Secretariat and Chair of the Health Sciences Research Ethics Committee of the University of the Free State at (051) 405 2812.

Thank you in advance for being willing to participate in the above mentioned study.

INLIGTINGSDOKUMENT

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

Beste Pasiënt

Ek, Liezel Naudé, is tans besig om navorsing te doen oor die faktore wat die ontwerp van 'n Arbeidsterapie program vir beroerte pasiënte, binne 'n landelike primêre gesondheidsorgomgewing binne die Thabo-Mofutsanyana Gesondheidstreek, sal beïnvloed. Navorsing is egter slegs die proses wat gebruik word om 'n vraag te beantwoord en in hierdie studie wil ek die verskillende faktore navors wat die belang en uitvoerbaarheid van 'n arbeidsterapie geïntegreerde benadering vir beroerte pasiënte sal beïnvloed. Ek poog om die navorsing uit te voer deur die hulp van beroerte pasiënte wat bekend is met arbeidsterapiedienste wat op 'n Distriksvlak gelewer word. Die doel van hierdie studie is om 'n dokument saam te stel met die faktore wat die ontwerp van 'n arbeidsterapie program vir beroerte pasiënte sal rig in die toekoms. Hierdie studie het ontstaan vanuit die hernude fokus wat geplaas word op herstrukturering van die primêre gesondheidstelsel in Suid-Afrika asook internasionaal. Hierdie studie het dus ten doel om die huidige uitdagings aan te spreek wanneer arbeidsterapie dienste aan beroerte pasiënte gelewer word in 'n landelike primêre gesondheidsorg omgewing.

Uitnodiging tot deelname:

U word vriendelik uitgenooi om deel te neem aan hierdie studie. Deelname aan die studie is vrywillig en weiering om aan die studie deel te neem hou geen verliese of straf tot voordele waarop u geregtig is, in nie. U mag enige tyd van die studie onttrek sonder verlies van voordele. U absolute eerlikheid is noodsaaklik wanneer u die vrae beantwoord, om sodoende geldigheid van die resultate te verseker.

Wat die studie behels:

Die navorser gaan 'n wetenskaplike ontwerp navorsings metodologie gebruik in die uitvoering van die navorsing. As deel van die navorsingsproses sal deelnemers gevra word om aan 'n een-tot-een semi-gestruktureerde onderhoud met die navorser deel te neem. Die onderhoud sal vir ongeveer 'n uur duur en sal in Afrikaans, Engels en/of Sotho aangebied word. Daar sal 'n vertaler beskikbaar wees tydens die onderhoud. Die onderhoud sal opgeneem word en die navorser sal ook notas tydens die onderhoud neem. Na afloop van die onderhoud sal die opname op 'n eksterne hardeskyf afgelaai word en in 'n veilige, toesluitbare area gestoor word om konfidensialiteit te verseker. Die opname sal getranskribeer word vir die doeleindes van data analise.

Risiko's en voordele van deelname aan die studie:

Die studie hou geen fisiese gevare vir pasiënte in nie en geen vergoeding sal aan deelnemers betaal word nie. Die voordele van deelname aan die studie sluit in dat u die navorser bystaan om die faktore te identifiseer en te beskryf wat die ontwerp van 'n Arbeidsterapie geïntegreerde benadering vir beroerte pasiënte, sal beïnvloed. Neem

asseblief kennis dat die resultate van die studie moontlik gepubliseer kan word na afloop van die studie.

Etiese aspekte en konfidensialiteit:

Goedkeuring is ontvang van die Gesondheids Wetenskappe Navorsings Etiekkomitee van die Universiteit van die Vrystaat. Persoonlike inligting sal te alle tye vertroulik gehou word en inligting wat ingesamel word sal in geen stadium aan 'n individu gekoppel word nie. Alle inligting wat ingesamel word sal ge-depersonifiseer word.

Kontakbesonderhede van die navorser:

Indien u enige addisionele inligting benodig, kontak asseblief die navorser op 0726063058 of stuur 'n e-pos na liezel.naude22@gmail.com.

Vir enige navrae rakende u regte as 'n deelnemer, probleme of klagtes, kontak asseblief die Sekretariaat of Voorsitter van die Gesondheids Wetenskappe Navorsings Etiekkomitee van die Universiteit van die Vrystaat op (051) 405 2812.

Byvoorbaat dank vir 'n deelname in die bogenoemde studie.

TOKOMANE YA TLHAHISOLESING

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

Mokudi

Nna, Liezel Naudé, ke etsa diphuputso mabapi le dintlha tse tla ama ho ralwa ha lenaneo la Kalafo ya Tshebetso le ka sebediswang bakeng sa kalafo ya bakudi ba seterouku maemong a Tlhokomelo ya Motheo ya Bophelo bo Botle ya mahaeng Seterekeng sa Bophelo bo Botle sa Thabo-Mofutsanyana. Phuputso ke feela tsela ya ho ithuta karabo ya potso mme phuputsong ena ke batla ho ithuta hore na ke dintlha dife tse tla ama ho hlokahala le menyetla ya katleho ya lenaneo la keno-dipakeng la Kalafo ya Tshebetso bakeng sa bakudi ba seterouku ba tsejwang ke ditshebeletso tsa kalafo ya tshebetso boemong ba Setereke. Sepheo sa phuputso ena ke ho hlophisa tokomane e nang le dintlha tse tla susumetsa le ho tataisa mofuputsi ho raleng lenaneo la kalafo ya tshebetso bakeng sa bakudi ba seterouku kamoso. Phuputso e hlaha ho tsepamiso e ntjhafaditsweng e thehilweng hodima tekolo-botjha ya ditshebeletso tsa tlhokomelo ya motheo ya bophelo bo botjha Afrika Borwa ka bophara hammoho le matjhabeng. Kahoo, phuputso ena e batla ho sebetsana le diphepetso tsa hona jwale tseo ho shebanweng le tsona ha ho fanwa ka ditshebeletso tsa kalafo ya tshebetso ho bakudi ba seterouku boemong ba Tlhokomelo ya Motheo ya Bophelo bo Botle.

Memo ya ho nka karolo:

O mengwa ho nka karolo phuputsong. Bonkakarolo phuputsong ke ka boithaopo mme ho hana ho nka karolo ho ke ke ha baka tahlehelo kapa kotlo melemong eo o nang le tokelo ho yona. O ka ikgula bonkakarolong ka nako efe kapa efe ntle le tahlehelo ya melemo. Ho hlokahala botshepeho bo phethahetseng ha o araba dipotso, ho netefatsa bonnete ba diphetho.

Phuputso e kenyeletsa eng:

Ho tla sebediswa tsela ya patlisiso ya moralo wa saense. Jwaloka karolo ya tshebetso ya phuputso, bankakarolo bohle ba tla koptjwa ho nka karolo inthavuweng e batlang e hlophisitswe ya motho ka bomong le mofuputsi. Dipotso di tla botswa ka seAfrikaans, Senyesemane le/kapa Sesotho. Ho tla ba le mofetoledi mme inthavu e tla nka nako e ka bang hora e le nngwe ho e phethela. Inthavu e tla hatiswa mme mofuputsi o tla ngola dinoutsu ha e ntse e tswelapele. Kamora inthavu, kgatiso ya yona e tla kengwa ho polokelo ya *external drive* mme e bolokwe sebakeng se bolokehileng se kgonang ho notlelwa ho netefatsa poloko ya sephiri. Kgatiso e boetse e tla ngolwa fatshe bakeng sa manollo ya tlhahisoleseding.

Dikotsi le melemo ya ho nka karolo phuputsong:

Ha hona dikotsi tsa mmele tsa phuputso mme ha ho ditjeo tse tla lefuwa ho bankakarolo. Leha ho le jwalo, bankakarolo ba tla buseletswa tjhelete bakeng sa ditshenyehelo tsa maeto a ho nka karolo phuputsong. Melemo ya ho nka karolo phuputsong e kenyeletsa ho thusa mofuputsi ho hlwaya le ho hlalosa dintlha tse tla

susumetsa ho ralwa ha lenaneo la keno-dipakeng la Kalafo ya Tshebetso bakeng sa bakudi ba seterouku. Ka kopo lemoha hore diphetho tsa phuputso ena di kanna tsa hlalisoa kamora hore phuputso e fele.

Dintlha tsa boitshwaro le sephiri:

Tumello e fumanwe ho tswa ho Komiti ya Boitshwaro ya Diphuputso tsa Disaense tsa Bophelo bo botle ya Yunivesithi ya Foreisitata. Tlhahisoleseding ya motho e tla bolokwa e le sephiri ka dinako tsohle mme tlhahisoleseding e arolelanwang e ke ke ya amahangwa le motho ya itseng ka nako efe kapa efe. Tlhahisoleseding yohle e bokeletswang e tla tlotswa dintlha tsa boitsebiso.

Dintlha tsa boiteanyo tsa mofuputsi:

Ha o ka hloka tlhahisoleseding efe kapa efe e eketsehileng, ka kopo iteanye le mofuputsi ho 0726063058 kapa o mo romele imeile ho liezel.naude22@gmail.com.

Bakeng sa dipotso mabapi le ditokelo tsa hao jwaloka monkakarolo, mathata kapa ditlitlebo, o ka iteanya le Mongodi le Modulasetulo wa Komiti ya Boitshwaro ya Diphuputso tsa Disaense tsa Bophelo bo botle ya Yunivesithi ya Foreisitata ho (051) 405 2812.

Re leboha thahasello ya hao ya ho nka karolo phuputsong e boletsweng kahodimo.

ANNEXURE N - CONSENT FORMS FOR STROKE SURVIVORS

CONSENT TO PARTICIPATE IN RESEARCH

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

You have been asked to participate in a research study. You have been informed about the study by the researcher, Me L Naudé.

You may contact Me L Naudé at 0726063058 any time if you have questions about the research or if you experience any discomfort as a result of the research.

You may also contact the Secretariat of the Health Sciences Research Ethics Committee of the University of the Free State at telephone number (051) 4052812 if you have questions about your rights as a research subject.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate.

Signature of Participant

Date

Signature of Witness

Date

Signature of Translator

Date

TOESTEMMING TOT DEELNAME AAN NAVORSING

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

U is versoek om aan 'n navorsingstudie deel te neem. U is deur die navorser, Mej. L Naudé, ingelig oor die studie.

U kan Mej. Naudé enige tyd kontak indien u enige vrae het oor die navorsing of as u enige ongemak ervaar het weens deelname aan die navorsing. Die kontaknommer: 0726063058.

U kan ook die Sekretariaat van die Gesondheids Wetenskappe Navorsings Etiekkomitee van die Universiteit van die Vrystaat skakel by kontaknommer (051) 405 2812 indien u enige navrae het oor u regte as 'n deelnemer aan die navorsing.

U deelname aan hierdie navorsing is vrywillig en u sal nie benadeel word of voordele verloor indien u weier om deel te neem of u deelname aan die studie staak nie.

Indien u toestemming gee tot deelname aan die studie, sal u 'n getekende afskrif van hierdie dokument ontvang asook die inligtingsdokument wat 'n opsomming van die navorsing bevat.

Hierdie navorsingstudie sowel as die inligting hierbo vervat, is verbaal aan my beskryf. Ek verstaan wat deelname aan die studie behels en ook dat ek vrywillig instem tot deelname aan die studie.

Handtekening van deelnemer

Datum

Handtekening van getuie

Datum

Handtekening van tolk

Datum

TUMELLO YA HO NKA KAROLO PHUPUTSONG

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

O kopilwe ho nka karolo phuputsong ya boithuto. O bolelletswe ka phuputso ke mofuputsi, Me L Naudé.

O ka iteanya le Me L Naudé ho 0726063058 ka nako efe kapa efe haeba o na le dipotso mabapi le phuputso kapa haeba o ba le makukuno afe kapa afe ka lebaka la phuputso.

O boetse o ka iteanya le Mongodi wa Komiti ya Boitshwaro ya Diphuputso tsa Disaense tsa Bophelo bo botle ya Yunivesithi ya Foreisitata nomorong ya mohala (051) 4052812 haeba o na le dipotso mabapi le ditokelo tsa hao jwaloka monkakarolo wa phuputso.

Bonkakarolo ba hao phuputsong ke ka boithapo, mme o ke ke wa fuwa kotlo kapa wa lahlehelwa ke melemo haeba o hana ho nka karolo kapa o nka qeto ya ho ikgula.

Haeba o dumela ho nka karolo, o tla fuwa khophi e tekennweng ya tokomane ena hammoho le leqephe la tlhahisoleseding ya monkakarolo, e leng kgutsufatso e ngotsweng ya phuputso.

Phuputso ya boithuto, hammoho le tlhahisoleseding e ka hodimo ke e hlaloseditswe ka molomo. Ke utlwisisa hore na bonkakarolo ba ka phuputsong bo bolelang mme ke dumela ka boithaopo ho nka karolo.

Tekeno ya Monkakarolo

Mohla

Tekeno ya Paki

Mohla

Tekeno ya Mofetoledi

Mohla

ANNEXURE O - REIMBURSEMENT FORM FOR STROKE SURVIVORS

CONFIRMATION OF REIMBURSEMENT FOR TRAVEL EXPENSES

RECEIVED

Factors influencing the relevance and feasibility of the design of an Occupational Therapy stroke program in Primary Health Care

Dear Patient

You have been asked to participate in the above mentioned research study. You have been informed about the study by the researcher, Me L Naudé.

In order to participate in the study, you have encountered travel expenses in order to reach your closest health care facility.

You are hereby confirming that you have received R_____ from Me L Naudé, the researcher, to reimburse your travel expenses.

Signature of Participant

Date

Signature of Researcher

Date

Signature of Witness

Date