

UNIVERSITY OF THE WESTERN CAPE
Faculty of Community and Health Sciences



**THE ADAPTATION AND CONTEXTUALIZATION OF THE BRIDGES
STROKE SELF-MANAGEMENT INTERVENTION FOR PATIENTS
LIVING WITH STROKE IN THE WESTERN CAPE, SOUTH AFRICA.**

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SUPERVISOR

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ABSTRACT

Background: Many patients with stroke feel ill-prepared for discharge from stroke rehabilitation, despite having undergone extensive periods of therapy. From the available research, there is clear evidence that disease specific self-management interventions (SMI) are effective at changing targeted behavioural outcomes, and ultimately improve patient participation restrictions, using self-efficacy principles. A stroke SMI, originally developed by the Bridges Organization to address participation restriction in patients living with stroke in the United Kingdom (UK); was successfully adapted and contextualized for the New Zealand stroke population. A similar stroke SMI could have equal positive benefits for the South African stroke population but would need to be contextually relevant.

Aim: This study aims to adapt and contextualize the original UK Bridges stroke SMI workbook for implementation with the South African stroke population.

Method: The qualitative, exploratory study is conducted in five phases. Thirteen healthcare professionals (Phase 1) and 12 patients with stroke (Phase 2) are engaged with by the researcher using focus group discussions to understand their views on the implementation of self-management intervention in the local context; and one-on-one interviews with local South African patients living with stroke are conducted to explore their experiences (Phase 3) and build contextually relevant local vignettes. The adaptation and contextualization process of the Bridges stroke SMI workbook to the South African context occurs using the participant feedback and built vignettes from Phases 1 to 3. Consensus on the adaptation of the workbook is then reached through the use of an expert panel for peer-review (Phase 4), and a final focus group discussion with local healthcare professionals in the field of stroke rehabilitation (Phase 5) to produce the final South African Bridges stroke SMI workbook. Phase 1 and 5 participants were conveniently selected; while purposive sampling was applied for Phases 2 and 3. Throughout the various study phases, a thematic analysis procedure is employed by the researcher to analyse and interpret the themes identified through the qualitative data collected. A deductive approach was employed by the researcher for the focus group discussion data of Phase 1, 2, and 5; and an inductive approach to the data from the interviews in Phase 3. The trustworthiness criteria of credibility, transferability, dependability, and confirmability were applied.

Results: Phase 1 and 2 produce a number of themes that require consideration by the researcher for adaptation and contextualization. With the recommended adaptations being the addition of five South African vignettes, the inclusion of South African contextually rich and relevant pictures, and the addition of a 'Stroke Education' chapter. Phase 3 produces seven overarching themes that were clearly identified as being integral to the journey of South African patients with stroke; with five local vignettes being developed from the experiences of South African patients with stroke for use in the South African Bridges stroke SMI workbook. Phase 4 and 5 refine the adapted and contextualized South African version of the workbook through three stages. Stage one of the adaptation and contextualization process saw the production of the first draft of the South African Bridges stroke SMI workbook. Stage two of the adaptation and contextualization process saw the draft South African Bridges stroke SMI workbook being peer-reviewed by experts in self-management and stroke SMI workbook. Changes at this stage included: the removal of images where permission was not granted and ensuring compliance with intellectual property rights; recognition of appropriate stakeholders in the workbook; new high-quality images of the participants being required; limiting the use of the word 'expert'; and descriptors for the useful contacts section were added. In stage three, the consultation process with the local neurological healthcare professionals on the final draft South African Bridges stroke SMI workbook, yielded several recommendations for changes, including: additional workbook guidance, content wording needing to be more aphasia-friendly; and the use of patient words verbatim. Limited ethnic and functional diversity in the content of the vignettes was noted by the participants.

Conclusion: The components of an adapted and contextualized South African Bridges stroke SMI workbook for patients living with stroke in the Western Cape, South Africa needs to include vignettes that are contextually relevant. It is therefore important that the content, wording, and pictures of the vignettes are reflective of the local context. The self-management intervention should include stroke-specific health education. The current thesis produced the first ever South African Bridges stroke SMI workbook.

Keywords: Bridges, South Africa, Stroke, Self-Management Intervention

DECLARATION

I, Ryan Clive Groenewald, declare that this dissertation is my own work. It is being submitted for the degree Doctor of Philosophy in Physiotherapy at the University of the Western Cape, Cape Town. It has not been submitted before for any degree or examination at this or any other university.

R. Groenewald

Ryan Clive Groenewald

30th of November, 2018.



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DEDICATION:

To my remarkable wife, Michelle; handsome son, Joshua; and beautiful daughter, Emily; for your unwavering and endless love and support towards me always...



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First and always foremost, to God be all the glory and praise; it is only with Your strength that this research is possible.

To my research supervisor, Professor Anthea Rhoda, we have walked a wonderful and stressful research journey together; made all the better though for walking it with you. Thank you for all your time, wisdom, and guidance throughout this process; I am indebted to you.

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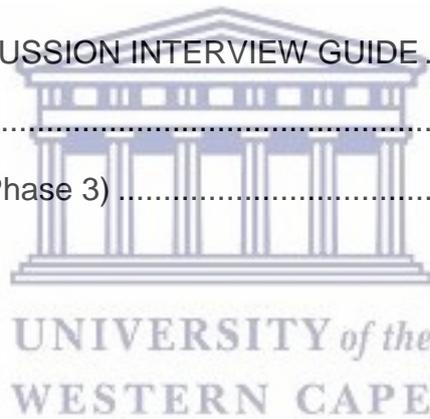
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LIST OF ABBREVIATIONS

ADLs	Activities of Daily Living
AHA	American Heart Association
ASA	American Stroke Association
BADLs	Basic Activities of Daily Living
BMH	Booth Memorial Hospital
CBR	Community-Based Rehabilitation
CBS	Community-Based Services
CDC	The Centre for Disease Control and Prevention
CNS	Central Nervous System
CPG	Clinical Practice Guidelines
CVA	Cerebrovascular Accident
CVD	Cerebrovascular Diseases
DALYs	Disability Adjusted Life Years
FGD	Focus Group Discussion
HCBS	Home and Community-Based Service
HCP	Healthcare Professional
HIV	Human Immunodeficiency Virus
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability and Health
INDS	Integrated National Disability Strategy
IOM	Institute of Medicine
IP	Intellectual Property
IS	Ischaemic Stroke
LEIC	Life Esidimeni Intermediate Care
LMIC	Low- and Middle-Income Country
LOS	Length of Stay
MDG	Millennium Development Goal
MDT	Multidisciplinary Team
MPDH	Mitchells Plain District Hospital
NCD	Non-Communicable Disease
OPD	Out-Patient Department
PHC	Primary Health Care

QOL	Quality of Life
SA	South Africa
SMI	Self-Management Intervention
SMP	Self-Management Programme
UK	United Kingdom
WCDOH	Western Cape Department of Health
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organization
YLL	Years of Life Lost



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CHAPTER ONE

INTRODUCTION

1.0 INTRODUCTION

Chapter One begins with the 'Background to the study', in which the researcher reviews and explores the available literature in detail to provide the reader with a concept and rationale for the study. Stroke is explored first, with a focus on its epidemiology. A review of the International Classification of Functioning, Disability and Health (ICF) then follows; with a focus on functional impairments, activity and activity limitations, and participation and participation restrictions as it relates and interacts with this study. The role of self-efficacy in patients with stroke; post-stroke rehabilitation; and stroke self-management interventions complete the literature review exploration. In addition to this, Chapter One will outline the problem statement and the conceptual framework; the research question; and the aim and objectives of the study. The chapter ends with a short descriptive outline of the chapters to follow.

1.1 BACKGROUND TO THE STUDY

1.1.1 Stroke

Stroke, or a Cerebrovascular Accident (CVA), is defined by the World Health Organization (WHO, 2006, p.11) as: "a focal (or at times global) neurological impairment of sudden onset, lasting more than 24 hours (or leading to death), and of presumed vascular origin". Stroke forms part of the cardiovascular disease (CVD) category of non-communicable diseases (NCD). To better understand the impact of CVDs, and in particular stroke, one needs to look at its epidemiology. WHO (2014) described epidemiology as the study of distribution patterns and causes of health-related conditions or events, including disease; and the application of this study to the control of diseases and other health problems. In this study, stroke epidemiology refers to the mortality and morbidity, prevalence and incidence, risk factors, burden of stroke, and disability post stroke - which includes neurological impairments, activity limitations, and participation restrictions. CVDs are recognized as the number one

cause of death globally; with an estimated 17.7 million people dying from these specific diseases in 2015. Of these deaths, 6.7 million were directly attributed to stroke; and more than three quarters of these deaths occurred in low- and middle-income countries (WHO, 2017). According to Bertram et al. (2013) who used similar modelling techniques to measure incidence, approximately 75,000 strokes occur yearly in South Africa.

When looking at our local context, according to Bryer et al. (2010), stroke was declared a “catastrophic illness” in South Africa in 2007 by the Joint World Congress of Stroke. To understand why CVDs, in particular stroke, are so prevalent in South Africa (Bertram, 2013), it is important to first look at what the risk factors are behind stroke, and then the contextual risk factors affecting the South African population specifically.

Bryer et al. (2010) highlighted that the South African Comparative Risk Assessment Collaborating Group identified eight main risk factors to stroke in the South African population, which frequently co-exist, with attributable fractions in brackets: Hypertension (52%), tobacco (24%), excessive body weight (18%), high cholesterol (15%), physical inactivity (12%), low fruit and vegetable intake (12%), diabetes (8%), and alcohol (8%). Mendis et al. (2011) added that there are other risk factors that need to be accounted for, including: poverty and low educational and socioeconomic status, advancing age, gender, inherited (genetic) disposition or ethnicity, and psychological factors (e.g. stress, depression). It is worth noting that these other risk factors that need to be accounted for are not solely associated with South Africa but are rather for global consideration. As with many other countries, in the context of South Africa, the local population are at particular risk of developing a stroke due to the high prevalence of a number of behavioural, metabolic and contextual risk factors as presented above.

It is important to note that stroke is an immensely costly disease, not only due to the large numbers of premature deaths, but also the ongoing disability experienced by patients with stroke and the negative impact on families and caregivers; as well as the overall negative impact on healthcare services (WHO, 2006). At a micro and macro level, there is sufficient evidence to demonstrate that CVDs, like stroke, contribute to poverty, due to the enormous healthcare spending and high out-of-pocket expenditure; placing a substantial burden on the economy of these countries (WHO, 2016). Feigin et al. (2014) identified that, in 2010, stroke was the second leading cause

of death and the third most common cause of disability-adjusted life-years (DALYs) globally. Mendis et al. (2011) explained that DALY is a measure of overall burden, expressed as the number of years lost due to ill-health, disability, or premature death. Two thirds of all stroke deaths occur in low-to-middle income regions, such as sub-Saharan Africa, but the true burden of stroke does not lie in the high mortality rate, but rather the high morbidity rate, whereby up to 50% of patients with stroke are left chronically disabled (Connor et al., 2006).

This above point on the true burden of stroke being the high morbidity rate was echoed by both Saka et al. (2009) and Joseph et al. (2013). Saka et al. (2009) confirmed that the true burden of stroke is reflected in the high long-term morbidity rate, leaving a significant number of patients with stroke experiencing moderate to severe chronic disabilities; which results in these patients being reliant or dependent on others to assist with their activities of daily living (ADLs). Joseph et al. (2013), also identified that stroke not only results in long-term disability for the patient but has the further potential of impacting negatively on the family as stroke leads to a dependency on others for assistance with everyday activities.

Taking into consideration the disability and morbidity that is caused by stroke, in terms of DALYs lost, it is evident that many years of life of a patient with stroke are lost to disability. The World Health Statistics (2014) identified that stroke was the third leading cause of years of life lost (YLL) globally in 2012; and although there have been considerable gains made, the global aspiration to substantially reduce mortality and morbidity from millennium development goal (MDG) conditions has not yet been achieved in certain parts of the world and in particular, Sub-Saharan Africa. There is compelling evidence of the need to address the substantial and growing burden of premature mortality and morbidity caused by NCD, such as stroke, in South Africa as the world moves beyond the 2015 global health agenda. The International Classification of Functioning, Disability and Health (ICF) is an ideal framework to assist in achieving this aim through conceptualizing morbidity.

1.1.2 International Classification of Functioning, Disability and Health (ICF)

The ICF framework will be used in this study to contextualize the disability experienced post stroke as it has been internationally recognized as a standard to describe and

measure health and disability; and allows one to describe the impact of health conditions and health-related states, such as stroke (WHO, 2001). The ICF is based on the integration of the medical and social models of disability, therefore applying the bio-psychosocial approach. Functioning is conceptualized as a “Dynamic interaction between a person’s health condition, environmental factors, and personal factors” (WHO, 2013, p. 3). The WHO defines functioning and disability as “umbrella terms”, whereby functioning encompasses: “Body functions, body structures, activities and participation”; and disability encompasses: “Impairments, activity limitations and participation restrictions” (WHO, 2001, pp. 212-213). The National Institute for Health and Clinical Excellence (NICE) stated that stroke is the single largest cause of complex physical and cognitive impairment; with most patients living with moderate to severe chronic impairment, activity limitation and participation restrictions as a result (NICE, 2010).

To understand more comprehensively how the ICF can be used as a framework for understanding stroke, as the health condition in focus, it is important to first understand the terms that are used within the ICF itself. According to WHO (2013), the umbrella terms of functioning and disability within the ICF represent both positive and negative aspects of functioning from a biological, individual and social perspective. WHO (2001, pp. 212-213) further defined each term within the umbrella of functioning as follows: Body functions – “The physiological functions of body systems”. Body structures – “Anatomical parts of the body, such as organs, limbs and their components”. Activity – “The execution of a task or action by an individual”. Participation – “Involvement in a life situation”.

Each term under the umbrella of disability is defined by WHO (2001, pp. 212-213) as follows: Impairments – “Problems in body function and structure, such as significant deviation or loss”. Activity limitations – “Difficulties an individual may have in executing activities”. Participation restrictions – “Problems an individual may experience in involvement in life situations”. Robinson et al. (2011) explained that within the ICF model, body functions and structure, as well as the activities, participation and environmental factors can be identified and defined, whereas personal factors cannot. Below, Figure 1.1 depicts the relationship between the components of the ICF.

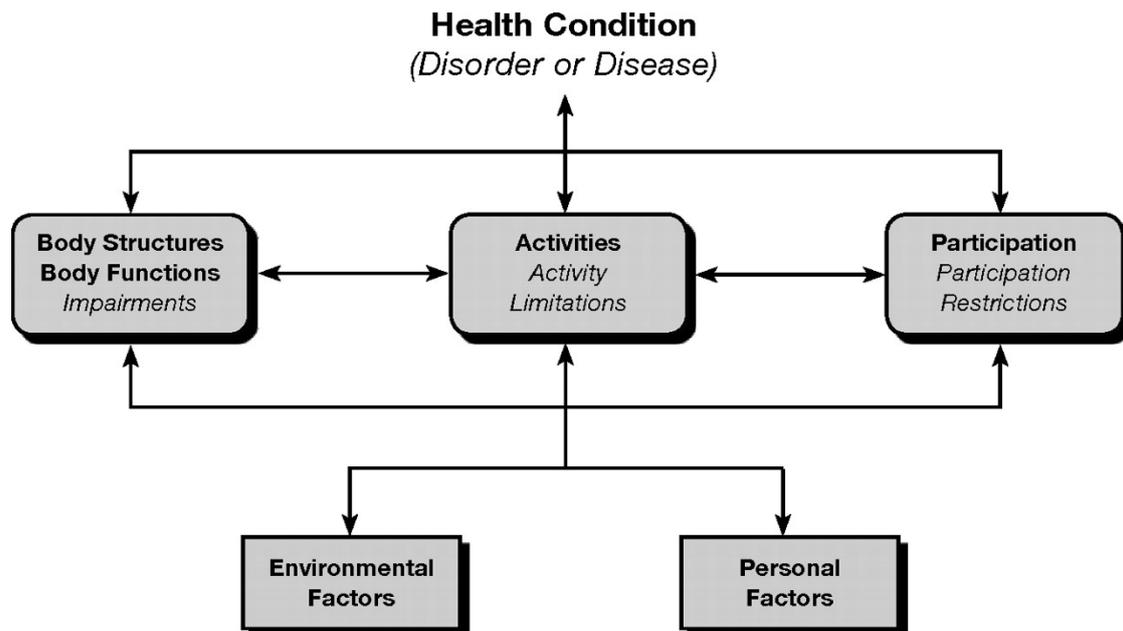


Figure 1.1: Interactions between the components of the ICF (WHO, 2001)

1.1.2.1 Functional Impairments

Staines et al. (2009) explained that the specificity of functional impairment following a stroke is heterogeneous; and varies depending on the particular regions of the central nervous system (CNS) that have sustained damage. WHO (2017) echoed this point explaining that the clinical presentation of functional impairment following a stroke depends largely on which part of the brain is injured, and how severely it is affected; with a very severe stroke potentially leading to sudden death. For patients who survive their stroke, Lo et al. (2013) explained that the stroke can have a profound negative impact, in terms of physical, cognitive, psychological, and social functioning.

When inspecting the specific functional impairments experienced by a patient with stroke, WHO (2006) identified several focal or global disturbances of the cerebral function that could be experienced and seen, either in isolation or in combination, namely: unilateral or bilateral motor impairment (including lack of coordination), unilateral or bilateral sensory impairment, aphasia or other communication disorders, hemianopia, forced gaze, apraxia of acute onset, ataxia of acute onset, and perception deficit of acute onset. Other possible associated symptoms that may be present, but are not adequate for stroke diagnosis, include dizziness or vertigo, localized

headache, blurred vision, diplopia, dysarthria, impaired cognitive functioning, impaired consciousness, seizures, and dysphagia. According to WHO (2017), the most common clinical presentation following a stroke however remains the sudden weakness or numbness of the face, arm or leg, most often restricted to one side of the body. Among the more common clinical presentations of physical impairments post stroke, the upper limb dysfunction remains an important hurdle for many stroke survivors; with only 5% of adult stroke survivors regaining full function of the upper limb, and 20% regaining no functional use (Staines et al., 2009). Half of all patients with stroke experience some degree of physical and or cognitive impairment post stroke; and the need for support for common activities of daily living (ADL) negatively impacts on the quality of life of the patient and their relatives (Di Carlo., 2009).

1.1.2.2 Activity and Activity Limitations

Hellstrom (2002) explained that findings in epidemiological studies, most of them conducted prospectively, are consistent in showing that the incidence of dependence in ADLs is highest immediately after a stroke (40-75%); and that the prevalence thereafter decreases to 57% at discharge, and 30% at one year, post onset. Further to this, Hellstrom (2002) highlighted that a general consensus surrounding activity is that the ADLs improvements in most patients with stroke are maximal within six months; and in fact, most of the recovery occurs within the first six to twelve weeks.

Badaru et al. (2013) identified that, in rehabilitation, the assessment of an individual's functional independence is used to identify disabilities in ADLs; whereby ADLs is considered the primary functional status measure due to its relative objectivity, simplicity and relevance to patients. Basic activities of daily living (BADLs) include: feeding, grooming, dressing, bathing, toileting, and transfers; whereas more complex instrumental activities of daily living (IADLs) include: mobility, hand function, work, and social participation. Two older, but not outdated studies, conducted by Hartman-Maeir et al. (2007) and Hofgren et al. (2007), presented their findings on the impact, one - year post stroke, on ADLs recovery. Hartman-Maeir et al. (2007) found that more than 50% of the patients with stroke, one- year post stroke, required mild to moderate assistance in BADLs including: dressing, bathing and the use of stairs. Whereas, most patients with stroke required full assistance in some areas of IADLs, including: meal preparation (77%), housekeeping (70%), and laundry (82%). Of the participants in the

study, only one could return to paid employment. Hofgren et al. (2007) conducted a similar study on 58 patients, 44 of whom were men and 14 women, aged 29-65 years. Of the participants, 51% had either neglect or aphasia at the time of their discharge. Improvement in cognitive function and in ADLs ability was seen; but one- year after discharge, the majority (83%) still had cognitive dysfunction, with 20% still dependent in ADLs. After one year, few had returned to work and at around three years after the stroke, only 20% were working (mostly part-time). Among the participants with neglect and/or aphasia, only 11% had returned to work, while 44% of patients without these deficits were working three years after the stroke. The occurrence of neurological deficits had a significant impact on the patient with stroke's ability to return to work.

In the context of Africa, and in particular South Africa, information on the functioning of patients with stroke is limited, especially at the level of activity limitations and participation restrictions (Rouillard et al., 2012). Rhoda et al. (2011) conducted a South African longitudinal observational study on 100 patients with stroke living in a community, to determine their activity limitations. The findings of the study found that, at six months post stroke, a majority of the participants could not manage to climb stairs, travel on public transport, wash dishes, do washing or other household chores, manage shopping, socialize, or manage their garden. The researcher did however note that significant improvement was found in the performance ability of the to manage with BADLs and IADLs between baseline and two months; but that this performance ability was limited between two and six months. Rhoda et al. (2011, p.16) concluded by indicating that, "Although the participants were able to perform BADLs, enabling them to be independent in their homes, they were unable to perform IADLs, which limited their functioning in the community". A more recent South African study, conducted by Cawood et al. (2016), on 53 chronic patients with stroke, statistically proved that muscle strength and motor function impairments post stroke did affect the participants' ability to perform ADLs like self-care, walking, stairs, and speech; which negatively impact on one's home-making ability, employment, leisure, and sport. It was further proven by Cawood et al. (2016) that perceptual and cognitive skills played a key role in performance of ADLs; which negatively impacted on activities and participation, and ultimately, the return to work.

Staines et al. (2009) stated that limitations post stroke arose not only because of neurological impairment, but also as a result of physical de-conditioning due to inactivity. With the increased energy demands associated with the performance of everyday activities among patients with stroke, this becomes increasingly problematic. The impact of physical de-conditioning on post-stroke impairment may further compromise health-related quality of life and increase the risk of recurrent stroke. Behavioural changes post stroke, such as avoidance of physical activity, further reduce aerobic capacity and impair sensorimotor control; leading to a cycle of reduced physical capacities and limited activity and participation that reinforces one another.

1.1.2.3 Participation and Participation Restrictions

Cawood et al. (2016) noted that 'participation', as defined by the ICF, encompasses the things that give meaning to peoples' lives, such as: employment, caring for family, sports, leisure activities, spiritual involvement, management of personal affairs, and community and civic activities. Robinson et al. (2011) highlighted that the ICF provides a conceptual framework for examining the factors that contribute to participation of patients with stroke; whereby the health condition, being stroke, has a number of physical and contextual factors that each offer important contributions to the recovery of community participation following stroke.

Vincent-Onabajo (2013) observed that social participation of patients with stroke, described as an individual's involvement in life situations, is a component of human functioning that reflects the complexity of a person's roles beyond the performance of ADLs. The dimensions of social participation, which include: community life, leisure, educational and occupational activities, social integration, and economic self-sufficiency, are all linked with an individual's well-being and quality of life (QOL). Hellstrom (2002) expounded on participation, indicating that, in most studies dealing with the social impact of stroke, QOL of survivors was focused on; and shows that restrictions in participation and depression following stroke are detrimental to QOL. A marked decline in active leisure participation is often experienced after stroke, regardless of motor function, and can affect leisure satisfaction.

Two older studies, conducted by Robinson-Smith et al. (2000) and Clarke et al. (1999), found that items such as: lack of a job, impaired sex life, inability to travel on vacation

and pursue leisure-time activities, gave lower rankings for post-stroke impact on QOL; whereas items relating to family, home and emotional support had higher impact rankings (Robinson-Smith et al., 2000). Clarke et al. (1999) further found that marital status was associated with perceived participation restrictions one- year post stroke; but that the effects varied in men and women. Men who were married reported fewer restrictions than unmarried men; while married women reported greater restrictions than unmarried women. Hellstrom (2002) highlighted that cognitive disability, and a history of previous stroke, were also found to contribute to participation restrictions in the later stages of recovery. A more recent longitudinal study by Mudzi et al. (2013, p.1) on 200 first-time patients with stroke, using valid and reliable outcome measures, identified that the participants experienced “severe to complete difficulty” when attempting single, or more than one, task without aid at 12 months post stroke; with difficulty noted in “preparation of meals, household work and interpersonal interactions, participation in community life and partaking in recreation and leisure activities”. From this study, Mudzi et al. (2013,) identified facilitators and barriers to community participation for patients with stroke, with facilitators including the attitudes of close family and societal attitude; and, barriers including friends, transportation services, and social security services.

Most patients with stroke are not able to resume their previous role in life or engage in the various activities as they did previously; with the stroke distinctly restricting their participation in everyday life and usual activities (Desrosiers et al., 2006). A South African study, conducted by Rouillard et al. (2012) on patients with stroke, found that a majority of the participants reported they were unable, or had a reduced ability, to participate in social and leisure activities (82.6%), work activities (60.8%) and family responsibilities (58.7%) respectively; with a further 37% reporting problems with relationships or feelings of isolation post stroke.

In a case-controlled design study conducted by Robinson et al. (2011), with 30 patients with stroke and 30 people without a stroke, it was identified that, while individual functional factors such as gait, balance, muscle strength and muscle length were associated with level of participation; personal factors, such as depression, cognition and self-efficacy may be a stronger determinant of participation in the community following stroke. Chau et al. (2009) explained that the long-term outcome of

participation for patients with stroke are determined by several psychosocial factors, including: depression, self-esteem, and social support. Robinson et al. (2011) further identified several likely reasons behind limited participation, or participation restrictions, of a patient with stroke in the community, with the need to be accompanied, and most notably, reduced self-efficacy focused on.

1.1.3 Role of Self-Efficacy in Patients with Stroke

Robinson et al. (2011) further indicated that the personal factors of a patient with stroke play a crucial role in functioning and health; and therefore, need to be considered in research and patient management. There is currently no consensus on which personal factors should be included in the ICF framework; however, the most common personal factors associated with participation outcomes include: increasing age, female gender, lower than high school education, medical comorbidities, lower socio-economic status, fatigue, quality of life, depression and self-efficacy (Robinson et al., 2011). Many of the personal factors listed above have been shown to significantly influence the functional ability of a patient with stroke and have been widely researched, as seen in studies conducted by Mayo et al. (2014), van der Zee et al. (2013), and Fallahpour et al. (2011), to name a few. Therefore, these personal factors will not be included in the aim and objectives of this study; but rather self-efficacy, which has not been extensively researched, will be the focus.

Riazi et al. (2014) explained that, due to disability post stroke, patients with stroke need to make adjustments to their lives and this can mean learning new behaviours and modifying lifestyles. The acquisition of these skills is dependent, not only on the quality and intensity of rehabilitation, but also on the individual's psychological state. Self-efficacy, as a psychological construct, plays a key role as a cognitive mediator of action, whereby higher levels of self-efficacy are associated with higher performance attainment, and can ultimately predict functional independence and participation post stroke (Riazi et al., 2014). Self-efficacy, which forms part of the Social Cognition Theory, is a concept that was first identified in the late 1970s as being influential in a person's decision to engage in or to avoid particular settings or activities. It was described by Bandura (1977) as a belief in one's capabilities to organize and execute the course of action required to produce certain outcomes. In the latest available literature on the concept of self-efficacy, Malouff (2013, p.12) defined it very broadly

as “the belief in one’s own ability to successfully accomplish something, achieve a goal”. LeBrasseur et al. (2006) found that self-efficacy is such an important aspect of a person’s behaviour that it is said to determine whether an individual will attempt an action or not; and whether they will persevere in overcoming perceived obstacles.

Hellstrom (2002, p.16) elaborated further that the cognitive notion of personal self-efficacy implicated three separate conceptual domains, including: “having tacit task knowledge and skills”; “having an explicit sense of confidence in one’s ability to mobilize the motivation and cognitive resources required to perform a specific task or skill”; and “having confidence in one’s ability to successfully execute a specific task or skill in a given context”. These three fundamentals, plus the magnitude of the value placed on the anticipated outcome by the individual, were deemed by Bandura as being powerful mediators underpinning an individual’s willingness and desire to implement a task or activity in any specific context.

Hellstrom (2002) however clarified that self-efficacy is a form of self-confidence that is situation-specific; whereby such beliefs are situational rather than static and can change over time as the individual changes. Individuals are characterized not simply according to their degree of general efficacy, but according to their efficacy within a specific activity; whereby individuals with high self-efficacy tend to tackle more challenging tasks, put forth more effort, and persist longer with a particular task in the face of aversive stimuli. However, in contrast, individuals with low self-efficacy tend to give up, attribute failure internally, and experience greater anxiety or depression. Barlow (2010) echoed these sentiments and identified that self-efficacy is an important factor to consider in relation to rehabilitation for people with disabilities, whereby the level of self-efficacy influences rehabilitation with regards to: the amount of effort patients will invest; their persistence despite facing challenges; whether they can maintain a positive attitude; and, the amount of stress experienced. Barlow (2010) concluded by indicating that self-efficacy is a dynamic concept that varies according to one’s own experiences; but can be viewed as a useful theory in the context of rehabilitation, since it provides a blue-print for how self-efficacy beliefs can be enhanced in individuals. Certain factors, as will be discussed below, can influence self-efficacy, and are therefore important to rehabilitation when considering a patient’s health in relation to their functional outcomes (Barlow, 2010).

Malouff (2013, p.13) explained that perceived self-efficacy can be influenced, positively and negatively, by four factors, namely: “mastery experience, vicarious experience, verbal or social persuasion, and somatic and emotional state”. The first, and most effective, factor to increase an individual’s self-efficacy is ‘mastery experience’, which occurs when one attempts to complete a task and is successful. Of paramount importance to this though is the fact that the individual feels that the task completion was of their own effort and not that of someone else’s. The second factor, ‘vicarious experience’, is the observation of the success and failures of other individuals viewed as being in a similar situation to one’s self. Individuals who watch others in a group training session can provide observational experiences that enhance self-efficacy, especially if the respective individuals are seen as similar. The third factor, ‘verbal or social persuasion’, is where individuals are more likely to attempt a task once persuaded verbally that they could achieve, or master said task. The fourth and final factor, ‘somatic and emotional state’, is where the individual’s physical and emotional state, when contemplating completing a task, provides clues as to the likelihood of their success or failure. Stress, anxiety, worry and fear all negatively affect self-efficacy and can lead to a self-fulfilling prophecy of failure or inability to complete tasks as feared. Malouff (2013) concluded by indicating that these four factors that affect self-efficacy, influence an individual’s behaviour and therefore, their functional outcomes in rehabilitation. A visual representation of the effect of the four factors on self-efficacy and functioning can be seen below in Figure 1.2.

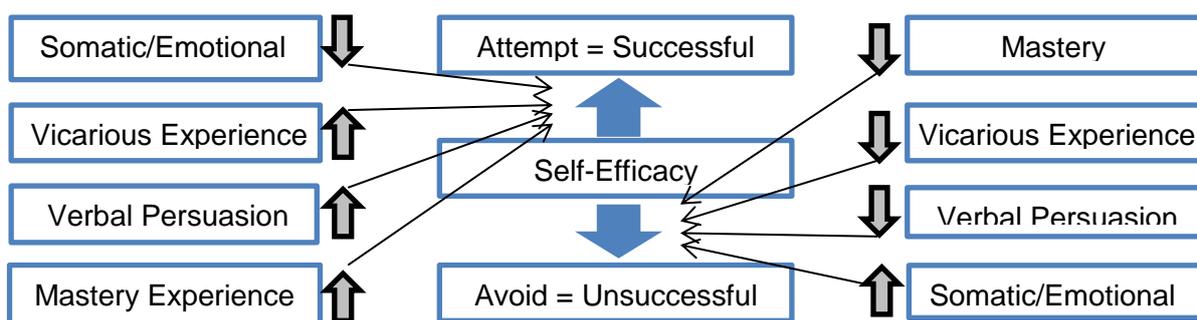


Figure 1.2: Self-efficacy theory (Malouff, 2013, p.18)

Maujean et al. (2014) highlighted that a key factor in determining outcomes once patients with stroke are living in the community, may be their belief about their ability

to overcome the difficulties they encounter. Preliminary research into the relationship between self-efficacy and recovery from stroke indicates that high self-efficacy has a positive influence on an individual's level of physical functioning; but limited research to date has considered the relationship between self-efficacy and other important domains of functioning, namely: the psychological, social, and instrumental aspects of daily living. Theoretically, the higher the level of self-efficacy in these domains, the better the functioning in daily living and, hence, in the overall adjustment and wellbeing of the affected individual.

1.1.4 Post Stroke Recovery and Rehabilitation

Staines et al. (2009, p.6) reported that, "following a cerebral insult, such as a cerebrovascular accident (CVA), the central nervous system (CNS) undergoes reorganization or plasticity during the process of neurophysiological recovery". However, the degree of this recovery, and the processes involved in this recovery, are incompletely understood. Hellstrom (2002) noted that the recovery of impairments post stroke, such as: motor function, sensation, perception and speech, are all representative of neurological recovery; and further highlighted that it is well established that the major part of the neurological recovery takes place within the first one to three months following stroke, while only minor changes are seen between three months and one year, post stroke. Staines et al. (2009) concurred, and further highlighted that the available literature indicates the neurophysiological changes associated with recovery often begin very early after the onset of stroke, generally within one to two weeks. The recovery over the first three months is shown to be the most rapid; however, functional recovery has been shown to progress even years after the stroke event, albeit at a much slower rate. Staines et al. (2009) emphasized that several factors can influence the rate and extent of recovery, with the most notable being the initial severity of the stroke, which is typically quantified clinically or functionally by the size and location of the lesion. Recovery can also be influenced by various characteristics of the individual affected by the stroke, particularly their age, comorbidities, activity patterns, and their participation in formal rehabilitation training.

Stroke rehabilitation is defined by The National Institute for Health and Clinical Excellence (NICE, 2010, p.2) as: "a reiterative, active, educational, and problem-solving process; focused on the individuals needs with the following components:

assessment, goal setting, intervention, and evaluation". Patients with stroke have a high burden of impairment, activity limitation and participation restriction post stroke, and much of the post-stroke care relies on rehabilitation interventions. The process of rehabilitation therefore aims to maximize the participation of the disabled person in their social setting; and to minimize the pain and distress experienced by the individual and their family or caregivers (NICE, 2010). Joseph et al. (2013) cited literature from the WHO (2001), which indicated within the past three decades there has been a deviation in the approach of stroke rehabilitation from being grounded in the medical model of disability, to the bio-psycho-social model (ICF) that is currently employed. This has meant that rehabilitation now focuses towards addressing outcomes that are of specific importance to the service user, which are often related to functional abilities and occupational duties. Joseph et al. (2013) emphasized that, "These functional abilities have become the reference framework against which meaningful outcomes for the patients are measured; and the impetus for the provision of rehabilitation services along the continuum of care, and not just intermittently on an in-patient basis".

Staines et al. (2009) however noted that questions remain about the mechanisms by which improvement is mediated; but that rehabilitation training has been shown to be critical in shaping reorganization within the CNS post stroke. Staines et al. (2009, p.6) stated that, "In both the healthy and injured CNS, the development and training of motor skills leads to rapid cortical adaptation characterised by shifts in central representation to meet new task demands"; and that, "During sensorimotor recovery from stroke, these normal training-related cortical adaptations can interact with and influence cortical reorganization associated with spontaneous recovery". Furthermore, for many of the post-stroke impairments, the key to minimizing disability is "rehabilitation to retrain patients to improve their capacity". Staines et al. (2009) emphasized that, while research continues to establish the most effective stroke rehabilitation techniques, the common theme among the more successful approaches is a requirement for patients to practice actively using their affected body part. In addition, the use of rehabilitation techniques needs to feature "increased challenges that are task-related, as opposed to simple movement repetition". In the last decade, there has been clear evidence of studies showing that such task-related motor retraining may lead to improved recovery by facilitating brain repair. It is important to recognize that focused patient-specific therapy is an important element to minimizing

post-stroke disability. Determinants of the relative success of such therapy, beyond the specific techniques applied, include the intensity of therapy, patient motivation/participation in the programme, and the timing of the therapy. It is becoming clear that more time directed at retraining following stroke, including patient-appropriate practise of tasks beyond the clinical setting, can enhance recovery (Staines et al., 2009).

Di Carlo (2009) however, highlighted that the process of recovery post stroke includes physical, psychological and social aspects; and can be both demanding and long-term. Maujean et al. (2014) further highlighted that, although stroke has a profound and wide-ranging effect on the physical, psychological and social aspects of an individual's daily life; the focus of healthcare professionals during their rehabilitation efforts, particularly immediately following stroke, is primarily on the individual's physical functioning. Difficulties in daily living, and the psychological and social problems experienced following a stroke, are often overlooked. As a result, stroke survivors are being discharged to the community and are left to face a new reality, which often includes having to cope with physical and/or cognitive impairments, dependence on others, loss of identity, social isolation, and diminished self-esteem. These issues often have devastating implications for the individual's perception of competency and efficacy in completion of daily living tasks.

In a book written by Stein et al. (2009, p. 400) on stroke recovery and rehabilitation, the authors state that the success of an exercise programme in patients with stroke, who are in the chronic phase, depends on a number of factors. These factors, which include several common psychosocial and behavioural factors, can become challenging and interrupt the continuity of health-promoting exercise programmes when patients with stroke transition between the sub-acute and chronic phase of stroke. Stein et al. (2009, p. 400) noted further that patients with stroke have a poor self-efficacy for exercise prescriptions, which predicts physical inactivity and reduced exercise behaviours in chronic stroke patients. Stein et al. (2009, p. 400) concluded by indicating that recommendations by healthcare professionals influence the exercise patterns of the disabled populations and, historically are under-utilized to promote activity in the chronic phase of stroke. These findings, which are consistent with social learning theories to promote exercise behaviours in patients with chronic diseases,

highlight the importance of education and behavioural strategies like self-management interventions, to overcome barriers to participation in the community.

Stroke rehabilitation can occur in various settings, depending on the appropriateness of the rehabilitation for the patient. The levels of the stroke rehabilitation for the local setting are described in 2.1.2. However, due to the nature of stroke and inherent long-term chronic disabilities, it is likely the patient will require ongoing community-based rehabilitation (CBR). Joseph et al. (2013) highlighted that stroke onset in the Western Cape of South Africa, takes place at a much younger age than persons in the developed world, which greatly underscores the longer time these individuals are required to live with, and manage, their disabilities in the community. In addition, “the likelihood of persons with stroke receiving lifelong or community-based rehabilitation, along with in-patient rehabilitation, is unlikely due to the highly-pressurized healthcare system in South Africa” (Joseph et al., 2013, p.647).

CBR is an approach to rehabilitation that has been widely recognized for many years, and was described in a joint paper by WHO, the International Labour Organisation (ILO) and the United Nations Educational, Scientific and Cultural Organisation (UNESCO) in 2004 as being: “a strategy within general community development for the rehabilitation, equalization of opportunities, and social inclusion of all people with disabilities” (ILO, UNESCO and WHO, 2004, p.2). In CBR, the resolution of impairments does not necessarily contribute significantly to the recovery of participation. Stroke CBR should therefore be aimed at spending more time training individuals, through self-management interventions (SMI), in advanced activities that require adaptations to manage encounters with complex conditions in the community so as to reduce participation restrictions and improve social interaction of patients with stroke (Robinson et al., 2011).

1.1.5 Self-Management Intervention (SMI)

Lo et al. (2013) explained that self-management refers to an individual’s “active participation in managing their own symptoms, treatment, physical and psychosocial consequences”, that are inherent in the aftermath of chronic illness; and that, due to the diverse recovery needs of patients with stroke, it is essential for these individuals to have adequate knowledge and skills for better self-management of their health

problems in daily living. In order to achieve effective self-management however, it is vital that individuals are actively involved in learning multiple self-management skills, which include: goal setting, action planning, problem-solving, decision making, information collection, resource utilization, collaboration, communication skills, and skills to maintain psychosocial well-being (Lo et al., 2013). This also requires a degree of self-efficacy on the part of the individual (Riazi et al., 2014).

Riazi et al. (2014) identified an increase in support, from the research community, for encouraging self-management in patients with stroke. As self-efficacy influences initiation of behaviour change, it has been implemented as the cornerstone of self-management interventions (SMI) or support programmes. Boger et al. (2012) recognized that SMIs are designed to empower individuals to manage their health more effectively; and that the engagement in SMIs by individuals with long-term chronic conditions, such as stroke, has been suggested to be the key to promoting recovery, empowering the individual, and facilitating improved health outcomes. de Silva (2011) confirmed that there is good evidence that supporting self-management works; and that self-management interventions designed for chronic conditions have shown a positive impact on quality of life, clinical outcomes, and overall healthcare service use. Jones et al. (2009) highlighted that, although there is clear evidence that disease specific SMIs, for individuals with chronic illnesses, are effective at changing targeted behavioural outcomes using self-efficacy principles, there was limited evidence specifically for patients with stroke.

Jones et al. (2009) found that many patients with stroke feel ill-prepared for discharge from stroke rehabilitation, despite having undergone extensive periods of therapy. Hale et al. (2014) however emphasized that, training of self-management techniques, together with mainstream clinical services, could offer new opportunities for patients with stroke to take charge of their rehabilitation and their lives; and if integrated effectively, could help address problems with confidence and the sense of abandonment many people experience after discharge from rehabilitation.

According to Lorig (2015) there are several self-management programs available aimed at addressing chronic disease of lifestyle; one being the Chronic Disease Self-Management Program, developed by Stanford Education Research Centre in the 1990's, which incorporated the self-efficacy theory. Kennedy et al. (2007) highlighted

that there is strong evidence that a tailored approach to self-management is ideal. A preliminary study was conducted by Jones et al. (2009), on community-dwelling patients with stroke in the United Kingdom (UK), using the Social Cognition Theory to support their self-developed stroke SMI, which sought to test the efficacy of a complex SMI in patients with stroke. The results of the study showed preliminary evidence that the use of an individualized stroke SMI was acceptable and could lead to a positive change of self-efficacy in patients with stroke.

From her research, Professor Fiona Jones created a social enterprise called “Bridges” that was launched in 2013; and is based at St Georges University in South-West London, United Kingdom (UK). From this social enterprise, the “Bridges Self-Management Programme” (SMP) was developed in 2014, which is aimed at supporting the integration of self-management interventions (SMI), in patients with long-term conditions such as stroke, into stroke rehabilitation programmes through healthcare professional – patient interactions. This Bridges SMP is focused on training and consultancy of healthcare practitioners, with the support of the co-produced Bridges SMI stroke workbooks, to support patients and their families in shared decision making, problem solving, and in attributing positive changes in their functioning and wellbeing to their own efforts rather than to their attending health professional (Hale et al., 2014). Jones et al. (2013) highlighted that the Bridges SMP is not a structured, didactic programme; but rather a philosophical approach that is integral to enabling patients with stroke to facilitate self-management principles in rehabilitation. These principles include: goal setting, action planning, problem-solving, decision making, information collection, resource utilization, collaboration, communication skills, and skills to maintain psychosocial well-being (Lo et al., 2013).

The original Bridges stroke SMI workbook, developed by the UK Bridges team, consists of an interactive workbook of eight sections; aimed at constructively impacting on the patient’s self-efficacy levels, and thereby positively impacting on their participation in life situations. The workbook starts by describing possible ways a patient with stroke may use the workbook. The second section encourages the user to reflect on their progress and achievements post stroke. The third section of the workbook contains the vignettes, which includes the experiences of patients living with stroke (contributors) in the UK. The fourth section describes common issues that are

experienced by patients with stroke, and some individual, personal solutions to managing them. The fifth section focuses on 'Keeping active' and encourages the user to try and do whatever it is they want to do to achieve their personal goals and targets. It also contains examples from the contributors regarding the different strategies used to maintain and enhance functional activity and participation. The sixth section encourages the user to plan for the future and hold onto their hope so as to motivate them. In the seventh section, the emphasis is on the user choosing targets of personal value and has sections that can be used to record the setting of, and reflection of, small personal weekly targets. The final section offers the user useful contacts to support their continued improvement.

SIMs, due to their nature of improving one's self efficacy, and encouraging individuals to manage their own symptoms, treatment, and lifestyle changes (Lennon et al., 2011), are preferred in resource constraint environments (such as in South Africa); as they empower and allow for the individual to take ownership of their healthcare and rehabilitation, and therefore reduce the burden of care on the limited available community healthcare rehabilitation resources. According to the Healthcare 2030 Road to Wellness report delivered by the Western Cape Department of Health (WCDOH, 2014), South Africa is in the process of re-imagining its approach to healthcare provision and service delivery; with the main focus and vision for 2030 being on achieving "A person-centred approach". This re-imagined approach sees a strengthening of the Primary Health Care (PHC) service platforms, of which HCBS are one - "A central tenet of the PHC philosophy is community involvement in health, which implies that the community takes ownership and responsibility for its own healthcare at a personal level". As part of this process, the WCDOH committed to advance the need for a "Philosophical and practical paradigm shift amongst healthcare workers from health 'providers' to health 'facilitators / enablers', in order to promote co-responsibility for increasing and sustaining wellness. This is important to remove the notion of dependency on health providers and to promote individual / community capacity and responsibility for the health and care of self and others" (WCDOH, 2014).

1.2 PROBLEM STATEMENT

In a systematic review of available literature, done by Jones et al. (2011), self-efficacy, the cornerstone of self-management interventions (SMI), was identified as an important variable associated with improvements in various outcomes, including ADLs and physical functioning, post stroke. In another comprehensive systematic review of available literature surrounding SMIs, with good methodological quality, Lo et al. (2013) found that trials on the effectiveness of self-management education interventions, for individuals with chronic illness, produced evidence to support the implementation of such interventions in the community setting. Proof of concept for the Bridges self-management programme (SMP) and its self-management intervention (SMI) workbook has been identified through several international feasibility research studies (Jones et al., 2009, 2016; & McKenna et al., 2013), as well as through qualitative research (McKenna et al., 2015), to be beneficial and acceptable from the perspective of patients with stroke, carers and healthcare professionals; with positive effects reported on the participation of patients living with stroke in the UK.

However, these SMIs are context specific; and to maintain the fidelity of the Bridges SMP, it cannot simply be transferred from one population to another (Personal communication with Prof. F. Jones, 2015). Bandura (1994) argued that self-efficacy and self-management concepts are socially constructed, and as a result can be influenced by cultural and contextual factors. Therefore, Cha et al. (2012) stressed that any SMI must be culturally acceptable. Lorig (2015) highlighted that several self-management programs have been adapted successfully from the Chronic Disease Self-Management Program, including the pain self-management program (Lefort, 1998), and the hepatitis-c self-management program (Groessl et al., 2010); but that “changes in format and length or large amounts of content cannot be met without rewriting and re-evaluating the new program format with a new population” (Lorig, 2015, p.2). Hale et al. (2014) explained that the Bridges SMI workbook was originally developed in close consultation with patients who had experienced a stroke in the UK; and that its cultural sensitivity had not yet been fully explored. Of particular concern is the relevance and appropriateness of the UK vignettes in the Bridges stroke SMI workbook that illustrate self-management strategies for people with different experiences of living with stroke in the UK. However, due to the potential the Bridges

stroke SMP and SMI workbook has to improve participation restrictions in patients living with stroke, Hale et al. (2014) conducted research whereby the original UK Bridges stroke SMI workbook was successfully adapted and contextualized for the stroke population in the New Zealand context.

Currently, in South Africa, for patients with stroke to receive interventions aimed at reducing participation restrictions after their discharge from acute and step-down facilities, they are required to attend home and community-based services (HCBS), as described above in Chapter 1, section 1.1.4. The HCBS is however limited and under extreme pressure throughout South Africa (Western Cape Department of Health, 2007); even though, according to a national Census 2011 on the 'Profile of Persons with Disabilities in South Africa', the Western Cape together with Gauteng, only has a prevalence of disability of 5.3% and 5.4% of the population respectively; with the Northern Cape and Free State having the highest prevalence of disability at 11.0% and 11.1% of the population respectively (Statistics South Africa, 2014). The HCBS, as with the entire South African healthcare system (Joseph et al., 2013), are often under-resourced, with long waiting lists; and can further exacerbate patient – healthcare professional dependency, which negatively impacts on the patient's functional improvement and restricts their participation level.

No study, in the local South African or even African context, could be identified from the available literature, incorporating the use of SMIs, especially as they relate to stroke-specific management. It is therefore hypothesized, based on the findings of Jones et al. (2009, 2016), McKenna et al. (2013 & 2015), and Hale et al. (2014) that a stroke SMI workbook could be adapted and contextualized for the resource constrained and healthcare professional dependent South African setting that could ultimately have similar beneficial and positive effects in addressing participation restrictions experienced by patients living with stroke in the Western Cape, South Africa; as well as going some way to assist in achieving the WCDOH's vision of 'a person-centred approach' to healthcare. It is with the above literature and evidence in mind that a knowledge gap has been identified.

1.3 CONCEPTUAL FRAMEWORK

The conceptual framework and objectives for this study will be guided by the protocol used by Hale et al. (2014), whereby the original UK Bridges stroke SMI workbook was successfully adapted and contextualized to the New Zealand setting. In their study, Hale et al. (2014) indicated that the description of their adaptation process could be used for introducing the programme into other contexts. Hale et al. (2014) followed a five-phase process of stakeholder consultation and qualitative methodology to identify the acceptance and relevance of the original Bridges stroke SMI for the New Zealand context as depicted below in Figure 1.3. Phase 1 involved consultancy with appropriate stakeholders and healthcare professionals (HCP) to discuss and explore the feasibility of the Bridges stroke SMP; and how it would be received and integrated into the current stroke care model. Phase 2 involved a focus group discussion (FGD) of patients with stroke to explore their responses to the Bridges stroke SMP; and to discuss what they felt would need to be changed in the workbook for its use in New Zealand. Conde et al. (2005) highlighted that, during the adaptation process of programmes, relevant stakeholders are both central and fundamental, as it is they who comprise the 'adaptation community' and who are required to sustain the process. Phase 3 was aimed at the collection of individual experiences of patients living with stroke in New Zealand for the purpose of inclusion as vignettes in the adapted workbook. Urimubenshi et al. (2011) emphasized that patients with stroke experience a number of environmental barriers that limit their reintegration, and therefore the overall experience of their stroke. In Phase 4, the researcher culturally and contextually adapted the workbook based on the feedback received from the participants in the first three stages. Finally, in Phase 5, the researchers piloted the adapted New Zealand Bridges stroke SMI workbook on the New Zealand stroke population to evaluate their perceptions of the intervention.

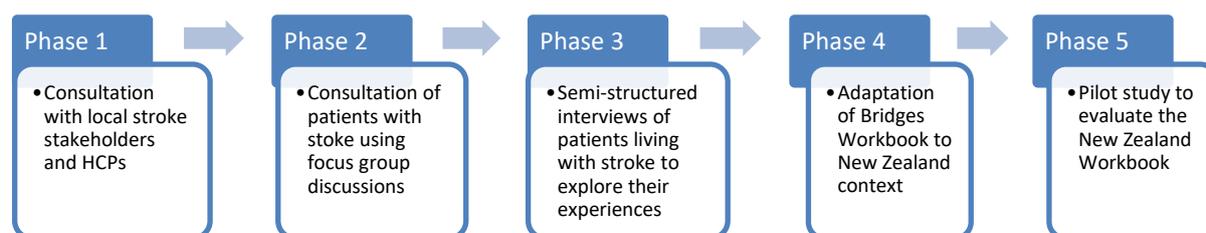


Figure 1.3: Five-phase process of New Zealand contextualization (Hale et al., 2014)

In this study, the researcher will follow a similar five-phase process of stakeholder consultation and qualitative methodology to identify the acceptance and relevance of the original UK Bridges stroke SMI for the South African context, and make the appropriate adaptation and contextualization as depicted below in Figure 1.4. The fifth phase of this research study however will detail the follow up consultation process with local HCPs on the developed final draft South African Bridges stroke SMI workbook.

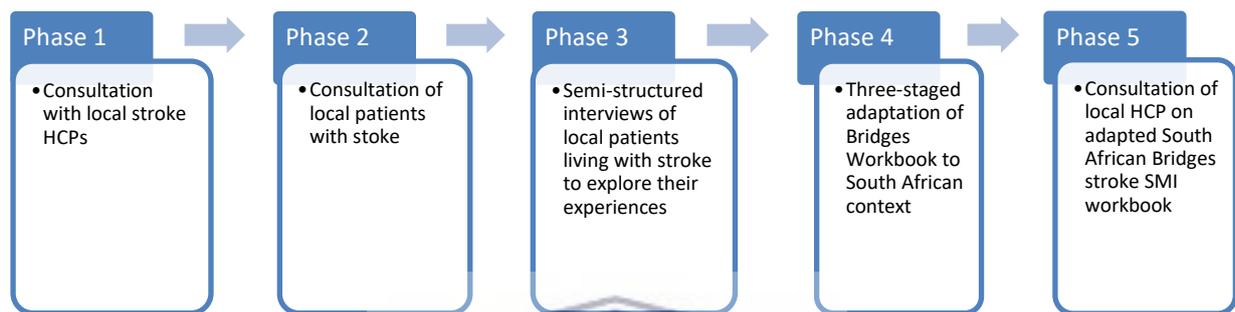


Figure 1.4: Five-phase process of South African contextualization

1.4 RESEARCH QUESTION

What components of the original UK Bridges SMI workbook are adapted and contextualized to produce a South African Bridges stroke SMI workbook for patients living with stroke in the Western Cape, South Africa?

1.5 RESEARCH AIM

To adapt and contextualize the original United Kingdom (UK) Bridges stroke self-management intervention (SMI) workbook for implementation with the South Africa stroke population.

1.6 RESEARCH OBJECTIVES

1.6.1 To explore local healthcare professionals' views on the implementation of the original UK Bridges stroke SMI workbook for the South African context.

- 1.6.2 To explore the views that South African patients with stroke have of the original UK Bridges stroke SMI workbook for the South African context.
- 1.6.3 To explore the experiences of South African patients living with a stroke for the purpose of inclusion in the adapted and contextualized South African Bridges stroke SMI Workbook.
- 1.6.4 To identify aspects of the original UK Bridges stroke SMI workbook that require adaptation and contextualization for the South African stroke population.

1.7 OUTLINE OF CHAPTERS

Chapter One frames the concept and rationale of the study in the reader's mind. It discusses the 'Background of the Study', with specific focus on a review of the available literature surrounding the important components as they relate to the study. Those components included: a review of stroke epidemiology, the ICF, the role of self-efficacy in patients with stroke, post-stroke rehabilitation, and stroke self-management interventions. In addition, this chapter outlined the problem statement and the conceptual framework; the research question; and the research aim and objectives of the study, to ensure the reader has clarity on the evolution of the study.

Chapter Two, being the 'Methodology' chapter, will describe and justify, in theoretical and empirical detail, the overall methodology of the study; highlighting various components incorporated into the framework, including: research setting, research approach and design, study population and sampling, research instruments, data collection, data analysis, and ethical considerations. Each subsequent chapter will also contain a brief methodology section of its own, to describe the processes followed for that specific phase of the study.

Chapter Three, being the 'Views on the implementation of a stroke SMI', which is the first and second phase of the study, unpacking the first and second objective, namely: 'To explore healthcare professionals' views on the implementation of the original UK Bridges stroke SMI workbook for the South African context'; and, 'To explore the views that South African patients with stroke have of the original UK Bridges stroke SMI

workbook for the South African context'. It explores the 'Background' of the objectives; contains a brief 'Methodology' of the processes followed; the 'Results' obtained during this process; the subsequent 'Discussion'; and finally, the chapter ends with the 'Summary'.

Chapter Four, being 'Building South African Vignettes', is the third phase of the study, which unpacks the third objective, namely: 'To explore the experiences of South African patients living with a stroke for the purpose of inclusion in the adapted and contextualized South African Bridges stroke SMI workbook'. The 'Background' of the objective is explored first; with the brief 'Methodology' section following; the 'Results' that were obtained are then presented; with the subsequent 'Discussion' being explained; and finally, the chapter ends with the 'Summary' of the objective.

Chapter Five, being the 'Adaptation and Contextualization', looks into the fourth and fifth phases of the study, which unpacks the fourth objective, namely: 'To identify aspects of the original UK Bridges stroke SMI workbook that require adaptation and contextualization for the South African stroke population'; as well as detailing the consultation with the HCPs on the adapted and contextualized final draft South African Bridges stroke SMI workbook. As with the previous chapters, the 'Background' of the objective is explored further first; the brief 'Methodology' of processes are explained; the 'Results' obtained during the process are highlighted; the subsequent 'Discussion' is presented; and finally, the chapter ends with the 'Summary'.

Chapter Six, being the 'Conclusion', is the final chapter of the study and summarizes the main points highlighted from all the previous chapters to ensure the reader has a complete picture and understanding of the study as a whole. The chapter also covers the 'Significance' and 'Limitations' to the study, as well as offering 'Recommendations' for further research.

CHAPTER TWO

METHODOLOGY

2.0 INTRODUCTION

This methodology chapter will describe and justify, in theoretical and empirical detail, various overall components incorporated into the framework of the study, including: the research setting; the research approach and design; the study population and sampling techniques used; the research instruments employed; the data collection methods and data analysis processes followed; and, the trustworthiness of the study. Finally, the chapter will end off with the ethical considerations implemented throughout this study. For ease of reading, each subsequent chapter will contain a brief methodology section of its own, to describe the process followed for that specific phase of the study.

2.1 RESEARCH SETTING

The description of the research setting below is provided to add to the understanding of the study's context; and to support both the investigations and findings of the study. The research setting for this study was Cape Town, in the Western Cape of Southern Africa. Two primary / step-down rehabilitation facilities, namely: Life Esidimeni Intermediate Care (LEIC) in Mitchells Plain, and Booth Memorial Hospital (BMH) in Oranjezicht, both offering intermediate care services, were identified by the researcher as being appropriate for use in this study; and were therefore employed as referral sites for recruiting participants into the study. The rationale behind using these two facilities for this research study is framed and explained by the researcher below. Specific venues were made available for data collections. These venues included therapy rooms (LEIC and BMH), conference room and participant's homes.

2.1.1 Locations

LEIC and BMH are found in two different communities of the Cape Metropole district of Cape Town, namely: Mitchells Plain and Oranjezicht; which allowed for a larger stroke population to be available for recruitment into the study; and were therefore identified by the researcher to be appropriate for use in this study.

2.1.2 Primary / Step Down Rehabilitation Level

In previous research conducted by Groenewald (2013), it was indicated that there are various levels of rehabilitation in the Cape Metropole area; with both in-patient and out-patient services offered through facility-based and community-based services. Services on these levels are available to population groups from various geographical locations across the Western Cape of South Africa.

Within the facility-based services in the Cape Metropole area, tertiary level rehabilitation, such as that offered by Mitchells Plain District Hospital (MPDH), is aimed at providing all individuals with short-term, intensive / high-care and or acute stage management of conditions, depending on the individual's requirements; until such time that the patient is stabilized and ready for discharge. Primary / step-down level rehabilitation, such as is offered by Life Esidimeni Intermediate Care (LEIC) and Booth Memorial Hospital (BMH), is aimed at lower intensity rehabilitation for sub-acute, stable patients who require further rehabilitation interventions; with a focus on reintegration of the patient back into their community. Secondary level rehabilitation, such as Western Cape Rehabilitation Centre (WCRC), is more specialized and aimed at individuals with a more permanent type of disability needing higher intensity rehabilitation, over an extended period of time. Within the community-based services (CBS), rehabilitation is offered through out-patient departments (OPD) at the community healthcare centres, such as Mitchells Plain Community Healthcare Centre, through home-based care personnel, and rehabilitation care workers.

The Bridges SMP and SMI workbook are designed to be used in all rehabilitation settings along the continuum of care; however, the researcher considered the various levels of rehabilitation settings to understand which would be most appropriate for this research study. With tertiary level rehabilitation, the short length of stay of a few days, the period of acute instability, as well as the acute nature of the stroke, would all have negatively impacted on the acquisition of useable data for the purpose of this research study; and was therefore not considered a viable option to use as a research setting in this study. With secondary level rehabilitation, due to the more specialized service and limited bed availability, more stringent and restrictive admission criteria are applied to the patients admitted into the available facility; limiting the accessibility for patients with stroke, and therefore limiting the inclusiveness of the stroke population

groups and subsequent data should research be conducted in a setting of this nature. However, rehabilitation at facilities on the primary / step down level, such as LEIC and BMH, have a longer length of stay of 42 days for their patients, and offer an appropriate source of potential participants, being patients with stroke from across the Western Cape, which allowed for the inclusion of stroke population groups representative of the province into the study, and were therefore deemed appropriate by the researcher.

2.1.3 Intermediate Care Service Provision

Intermediate Care, and its role in our current healthcare system in the Western Cape, is a fairly new concept to a number of people. The term 'Intermediate Care' has evolved to allow for an integrated provision of acute and sub-acute care, including: rehabilitation, palliative care, convalescent care and wound care. The description of Intermediate Care, as supplied by the Western Cape Department of Health (WCDOH, 2014), states that it is: "In-patient transitional care for children and adults, which facilitates optimal recovery from an acute illness or complications of a long-term condition; enabling users to regain skills and abilities in daily living. The ultimate discharge destination is home or an alternative supported living environment".

Intermediate Care therefore shifts the emphasis from a passive approach to healthcare, to a more active and rehabilitative approach; whereby clients are encouraged to function as independently as possible through a self-manage approach, while receiving adequate and appropriate support from the healthcare practitioners. In the Healthcare 2030 Road to Wellness report, the WCDOH stated that the focus in 2030 would be on strengthening the primary care providers' role as coordinators of patient care pathways across the health system, as they become the key mediators between the community and the other levels of care in the health system. Care pathways are of particular value where people have multiple morbidities and an array of interventions are required to support self-management (WCDOH, 2014). Below, Figure 2.1 depicts the three stages of the integrated care pathway a patient with stroke in the Western Cape is likely to follow when moving along the primary health continuum of care.

STAGES OF INTEGRATED CARE PATHWAY

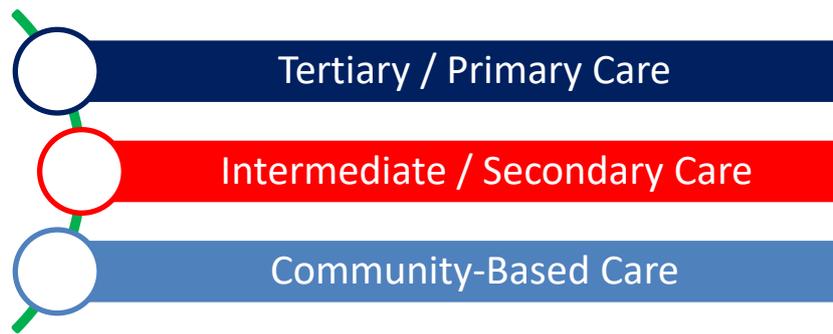


Figure 2.1: Integrated care pathway for patients with stroke in the Western Cape

Life Esidimeni Intermediate Care (LEIC) and Booth Memorial Hospital (BMH), are two such facilities that aim to achieve the above 'Intermediate Care' goals through the facilitation of a self-management approach; and are both equipped to manage a variety of patients and conditions from the four categories that fall under the Intermediate Care framework through the interventions of a multi-disciplinary team (MDT) of healthcare professionals (HCP). In particular, these two facilities are sufficiently equipped through their MDT rehabilitation approach and available resources to encourage and facilitate self-management of patients with stroke; and were therefore identified by the researcher as being appropriate for use in this research study.

2.2 RESEARCH APPROACH AND DESIGN

Lincoln and Guba (1985) highlighted that for qualitative research to be significant and of good quality, there needs to be a 'congruence' between the problem being investigated, the inquiry paradigm, and the context in which the research is conducted, for the inquiry to be able to produce meaningful results. Agostinho (2004, p.8-11) concurred, further highlighting that a review of the available literature indicates that assessing the quality of a qualitative research study is dependent on three factors, namely: "the appropriateness of the design used in the research to address the research problem"; "the process in which the inquiry is undertaken: that is, demonstrating rigor and how well the research process can facilitate truthful and accurate findings"; and, "the outcome of the research: that is, the usefulness of the research project to the community".

The researcher in this study endeavoured to produce good quality qualitative research through the application of a qualitative methodology, with an exploratory design. All approaches and frameworks implemented in the study are explored in more theoretical detail below.

2.2.1 Qualitative Methodology

Agostinho (2004) explained that qualitative research means many things to many people; and that it is a complex and evolving field of inquiry, which embraces a wide array of approaches, methods, and techniques. Given (2008) further explained that qualitative research is used to identify, analyse, and understand patterns of behaviours and social processes. According to Creswell (2013), qualitative research involves an interpretive, naturalistic approach; whereby incidences are studied in their natural setting, attempting to interpret phenomena in terms of the meaning people bring to them. Creswell (2013) further states that qualitative research starts with assumptions and the use of specific frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem. “To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analyses that is both inductive and deductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of the researcher, a complex description and interpretation of the problem, and its contribution to the literature or a call for change” (Creswell, 2013, p.44).

According to Creswell (2013), qualitative research is appropriate in situations whereby the researcher wants to explore a problem or issue further; and that the exploration is needed to identify variables that cannot be easily measured, to hear silenced voices, and or to gain a complex and detailed understanding of an issue. This detail can only be established by talking directly with people, engaging in their local environment, and empowering individuals to share their stories; thereby hearing their voice and minimizing the power relationship that often exists between researchers and participants. Creswell (2013) concluded by indicating that qualitative research is employed when partial or inadequate theories exist for certain populations and samples; or existing theories do not adequately capture the complexity of the problem

being examined. The above notions highlighted by Creswell ring true for this qualitative study under review.

Procedures of qualitative research, and its methodology, are characterized as being inductive, emerging, and shaped by the researcher's experience in collecting and analysing the data (Creswell, 2013). Eight common characteristics of qualitative research, which the researcher of this study endeavoured to observe during this research process, were identified by Creswell (2013, p.37-39). The first characteristic is that of "a natural setting"; whereby the researcher has face-to-face interactions so as to collect data in the field where the participants are experiencing their issue under study. The second notes the "researcher as a key instrument"; whereby the data was collected by the researcher through examining available documents, observing participants' behaviour, and interviewing participants using self-designed, open-ended research instruments. "Multiple methods" is the third characteristic; whereby the researcher relied on, and reviewed, data from more than a single source to organize it into categories or themes that correlate. The fourth characteristic notes "complex reasoning through inductive and deductive logic"; whereby the researcher built up patterns, categories and themes from the "bottom up", organizing the data inductively into increasingly more abstract units of formation. "Participants' meanings" is the fifth characteristic noted; whereby the researcher maintained a focus on learning the meaning that the participants held about the issue at hand (stroke self-management intervention implementation in South Africa), rather than the meaning the researcher attached to it. The sixth characteristic is that of qualitative research having an "emergent design"; whereby the initial research plan recognized the fact that all phases could possibly require a change or shift in focus once data collection started, which was observed in this study. "Reflexivity" is the seventh characteristic noted; whereby the researcher conveyed his background, how it informs his interpretation of the information in the study, and what he has to gain from the results of the study; all of which is described by the researcher in subsequent chapters and summarized in the final chapter. The eighth and final characteristic noted is that the researcher provides a "holistic account", while developing the complex picture of the issue being researched; which was achieved in this study by the researcher through reporting of multiple perspectives, identifying all factors involved, and outlining the larger picture that developed (Creswell, 2013, p.37-39).

Further to the above procedures and factors, Creswell (2013, p.45-47) provided several standards that a researcher should observe to ensure good qualitative research outcomes, namely: 1) “The researcher employs rigorous data collection procedures”; observed by the researcher in this study through the use of multiple rigorous data collection methods such as clearly defined focus group discussions, interviews and document reviews. 2) “The researcher frames the study within the assumptions and characteristics of the qualitative approach to research”, and 3) “The researcher uses a recognized approach to qualitative inquiry”; both observed respectively by the researcher during this study as detailed here in Chapter Two. 4) “The researcher begins with a single focus or concept being explored”; as depicted in this study through the focus being on the adaptation and contextualization of a self-management programme, with several single-focused objectives deriving from this concept. 5) “The study includes detailed methods, a rigorous approach to data collection, data analysis, and report writing”, observed by the researcher during this study as detailed here in Chapter Two. 6) “The researcher analyses data using multiple levels of abstraction”; as employed in this study through the implementation of deductive and inductive thematic analysis procedures to analyse the qualitative data. 7) “The researcher writes persuasively so that the reader experiences ‘being there’”; which the researcher in this study endeavoured to achieve. 8) “The study reflects the history, culture, and personal experiences of the researcher”; as observed throughout the narrative of the study. Finally, 9) “The qualitative research in a good study is ethical”; which was always a strong focus of the researcher in this study to ensure that the ethical management of the study and participants were of the highest regard. As highlighted above, the researcher in this study attempted to observe all the standards laid out by Creswell (2013) to achieve good quality research outcomes.

2.2.2 Exploratory Design

Gray (2014) noted that an exploratory study seeks to discover what is occurring and to ask questions around it; and is particularly useful when little is known about a specific event or occurrence. Furthermore, Gray (2014) found that an exploratory study is helpful when determining whether or not an issue is worth researching; and that exploratory studies could be conducted through several ways, including a search of the available literature, talking to experts in the field, or conducting focus groups.

Brown (2006) stated that the aim of an exploratory research design is not to provide the final conclusive answers to the research question, but merely explore the research topic to varying degrees; and that, exploratory research tends to look at newer problems on which little or no research has occurred. Dudovskiy (2016) concurred that this type of research is not intended to provide conclusive evidence; but rather, can be applied to allow for an expansion of knowledge around the issue in question. Dudovskiy (2016) emphasized that exploratory research is flexible and allows for adaptability to change; such that the researcher ought to be willing to change his/her direction as a result of the revelation of new data and new insights gained during the data collection process. Exploratory research can also be viewed as the groundwork research, which forms the basis of, and leads to, conclusive future research studies; helping by determining the most suitable research design, sampling methodology, and data collection method for the research (Dudovskiy, 2016). In this way, the exploratory research approach was most suited to achieve the objectives in this study.

Based on the above literature and processes, the researcher reasons that the research approach and design employed in this study was appropriate as the problem being investigated, the context of the research, the theory that reinforced the delivery of the research, and the research paradigm all demonstrated congruence. In addition, the researcher endeavoured to adhere to the characteristics and standards of a good qualitative research study, as laid out by Creswell (2013), so as to produce the most meaningful result.

2.3 SAMPLING METHOD

2.3.1 Phase 1 and 5 – Healthcare Professionals

Convenience sampling was employed for recruiting of healthcare professionals (HCP) as participants into the study during the first and fifth phases. Suen et al. (2014) explains that convenience sampling is used by researchers when participants, who are more accessible to the study, are included. Dudovskiy (2016) further clarifies that convenience or availability sampling is a type of non-probability sampling method that relies on data collection from participants who are conveniently available to participate in the study; and that no inclusion criteria are generally identified prior to the selection of participants. This sampling method, according to Dudovskiy (2016) is particularly

applicable in studies that require participants to give initial data regarding certain issues such as perceptions on new designs; and proves to be effective in exploratory stages of research. Several advantages and disadvantages of convenience sampling are highlighted by Dudovskiy (2016), with the advantages including: its simplicity of sampling; the fact that it is helpful in exploratory studies; data collection can be facilitated in a shorter duration of time; and it is the cheapest to implement over the alternative sampling methods. The disadvantages however include: its vulnerability to bias and influence beyond the control of the researcher; a high level of sampling error; and lower credibility as a result of the above. Based on the exploratory focus of this research study, and the fact that it is in line with similar research conducted on this topic (Hale et al., 2014); the advantages of the convenience sampling method were deemed appropriate for implementation in this study.

2.3.2 Phase 2 and 3 – Patients with Stroke

The researcher in this study employed purposive sampling for the recruiting of patients with stroke as participants into the study during Phases 2 and 3. Purposive sampling is typically used in qualitative studies, whereby the researcher carefully selects participants based on the study purpose, with the expectation that each participant will provide unique and rich information of value to the study (Suen et al., 2014). According to Crossman (2017), purposive sampling is a non-probability sample that is selected based on specific characteristics of the population and objectives of the study; and can be very useful in situations where a researcher needs to reach a targeted sample quickly, and where the proportionality of the sample is not the main concern. It is also a sampling method that is selected so as to provide a diverse range of cases relevant to a certain phenomenon and to provide as much insight as possible into the phenomenon under review (Crossman, 2017).

Purposive sampling method ensured that individuals with specific characteristics were included to present their views on the application of self-management, and specifically on the original UK Bridges stroke self-management intervention workbook in the local setting. The characteristics that were considered for purposive sampling in this case were: the participant's age, ethnicity, and severity of stroke; as well as, specifically for Phase 3 participants: community dwelling and whether they were willing to share their experience of living with a stroke. These characteristics were in line with those used

by Hale et al. (2014) in similar research; and were considered as being important for this study to ensure that appropriate patients with stroke, with sufficient diversity, were afforded the opportunity to provide their unique perspectives and views on the self-management intervention based on their experience of living with stroke in South Africa.

The participants were screened, prior to inclusion as potential participants into the study, using the following criteria: Diagnosed as having a first ever stroke, by a physician, based on the definition of stroke as seen in Chapter One (WHO, 2006, p.11); ≥ 18 years of age; having sufficient English language literacy ability and being of sufficient cognitive ability to actively participate with the English workbook, having a score of ≥ 24 points on mini-mental state examination as used by Graven et al. (2011); be medically stable; and in the sub-acute to chronic phase of their rehabilitation - six weeks to six months post stroke. This time period for inclusion of participants, as used in other similar research by Jones et al. (2009), was chosen based on the available literature by Kwakkel et al. (2013). Participants were excluded for consideration into the study if they were found to have cognitive or receptive language difficulties, which negatively impacted on their ability to engage actively with the intervention; and / or were found to have other known serious medical conditions that could negatively influence the findings of this study (HIV/AIDS, TB) due to their effects on the individual's body structure and functioning.

According to Dudovskiy (2016), the advantages of purposive sampling include: that it is one of the most cost- and time- effective sampling methods available; it is appropriate when limited number of primary data sources are available to contribute to the study; and, it is effective in exploration and discovery of meaning research. The disadvantages include: the fact that it is vulnerable to errors in judgement by the researcher; has a low level of reliability and high level of bias; and poor generalizability of research findings. Based on the exploratory nature of this inquiry, and the advantages highlighted; the researcher deemed it appropriate to employ the purposive sampling method during these two phases.

2.3.3 Phase 4 – Expert Panel

An expert panel was established by the researcher in Phase 4, using purposive sampling (Suen et al., 2014; Dudovskiy, 2016; and Crossman, 2017), for the purpose of reviewing and commenting on the adapted and contextualized draft South African Bridges stroke SMI workbook. This panel was made up of an ‘expert international support research team’ including: The UK Bridges programme founder and director; the principle researcher who successfully adapted and contextualized the original UK Bridges stroke SMI workbook for the New Zealand setting.

The National Institute for Health Research (NIHR, 2016, p.1) explained that, “expert review is the process through which research briefs, research proposals and final reports are critically assessed by relevant individuals unconnected to both the decision-making body and those who have prepared the material being assessed”. Furthermore, “it is an essential process that ensures only the highest quality research”; and, “the comments provided by reviewers inform the decision-making process and help to shape final research reports” (NIHR, 2016, p.2).

2.4 RESEARCH INSTRUMENTS

The research instruments used in this study included: an in-depth, structured, open-ended and self-developed focus group discussion interview guide (Annexure M), which was employed in Phase 1, 2 and 5; and, an in-depth, semi-structured, open-ended, one-on-one interview guide (Annexure N), which was employed in Phase 3.

2.4.1 Focus Group Discussion Interview Guide

Through the use of an in-depth, structured, open-ended, and self-developed focus group discussion (FGD) interview guide, made up of 12 broad questions, the researcher aimed to obtain feedback from the participants on their perceptions of the implementation of the original UK Bridges stroke SMI workbook in the local setting in Phases 1 and 2; while Phase 5 of the study aimed to obtain similar feedback, but on the adapted and contextualized South African Bridges stroke SMI workbook for the local setting. The guide was an adaptation of the two questions used by Hale et al. (2014) in their study. They asked participants to focus their discussions around whether the original UK Bridges stroke SMI programme was something the

participants thought the patients with stroke in New Zealand would be interested in; and, how they thought the workbook needed to be changed in order that it was contextually, socially, and culturally relevant for New Zealanders.

The researcher in this study aimed to obtain information regarding the required adaptations for the South African Bridges stroke SMI workbook. The FGD interview guide used in this study was therefore divided into four categories, namely: “General Workbook Layout”, “Workbook Content”, “Workbook User-Friendliness”, and “Implementation of the SMI in the South African Context”. This was done to ensure holistic feedback was received by all the focus group participants. The questions ensured that the feedback received was not only focused on the SMI concept and content of the workbook but also on the practical implementation and use of the workbook for the South African setting.

The researcher started the FGD interview guide by asking the participant two questions about the general layout, namely: 1) “How did you find the general layout of the workbook?”; and, 2) “How practical is the workbook in its design and feel?”. This was followed up by six questions as they relate to the content of the workbook, namely: 3) “What did you think of the overall content of the workbook?”; 4) “How appropriate and applicable were the stories to you?”; 5) “What stories stood out as being the most appropriate for you?”; 6) “What stories stood out as being the most inappropriate for you?”; 7) “How appropriate and applicable were the pictures to you?”; and, 8) “What would you change in the workbook?”. The researcher then proceeded to ask three questions about the user-friendliness of the workbook, namely: 9) “How did you find the overall user-friendliness of the workbook?”; 10) “Were you able to navigate or find the section or chapter you were looking for?”; and, 11) “Were you able to understand the flow of each section?”. The FGD interview guide concluded with the final question, 12) “What are your views on the implementation of this SMI in our local context?”.

2.4.2 Interview Guide

In the third phase, an in-depth, semi-structured, and open-ended, interview guide was used during the one-on-one interviews with the participants at their place of residence to explore their specific experiences of living with a stroke in South Africa. This interview guide was adapted from similar questions used by Jones et al. (2009) when

creating the original UK Bridges stroke SMI workbook, as well as questions used in the study by Hale et al. (2014) when adapting the original UK Bridges stroke SMI workbook. Hale et al. (2014) asked their participants five main questions, which included aspects of the participant's life experiences since the stroke, and how they had helped themselves; what challenges they had been faced with, and how they managed them; how they had helped themselves to improve their function and quality of life; how they found their hospital experience, and support after discharge; and finally, what advice they would give to someone else who had a stroke.

The participants of Phase 3 in this study were asked 12 main questions, with several sub-questions, to explain their experiences of living with a stroke in detail. The researcher started the interview with the first question, namely: "Tell me about yourself before the stroke; what did you like doing, what were you good at, can you give examples of things you have done in the past which have gone well, or you have overcome?"; this was followed up by the following questions: "How did you feel when you first learnt that you had a stroke?"; "Can you give some idea of how you manage day to day at the moment?"; "Can you tell us a bit about what happened to you, what you have been through, and some of your ups and downs?"; "Some people have stressed the need to get away from thinking about their health condition all the time, how do you do that - what works for you?"; "What is a small thing that makes a big difference to your life living with a stroke - how do you maintain being you?"; "How do you maintain or build relationships with family and friends - How do you interact with people?"; "What do you think about the support you have living in Cape Town, are there groups, clubs or support that you think is unique to here?"; "Can you give us any examples of the targets or steps you have set which have worked or haven't worked?"; "Lots of people like to have a list of hopes and dreams, is there anything that's really important to you which might take a bit of time, but you want to try and do?"; "How do you cope when you have lots of visits from healthcare staff, it can get overwhelming for some people - do you have any tips or ideas for others going through the same?"; and finally, the researcher ended the interview with the question: "What's the one thing you would like to tell someone in your position, such as a bit of advice, an idea, or a tip?". Figure 2.2 below summarizes the research instruments used during the phases of this study.

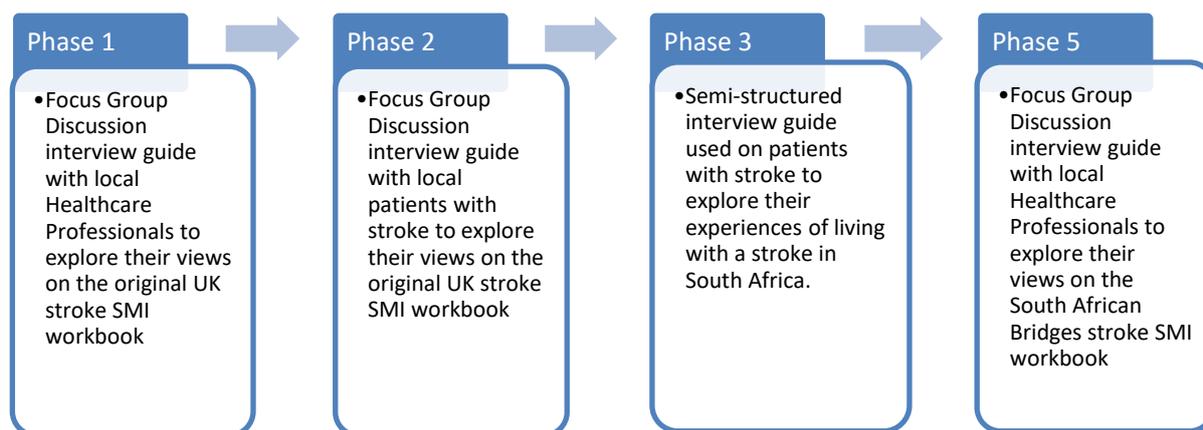


Figure 2.2: Research instruments used throughout the study

2.5 DATA COLLECTION METHODS

2.5.1 Phases 1, 2, and 5

The data collection method for Phase 1, 2 and 5 of this study was through the implementation of focus group discussions (FGD) with the healthcare professional (HCP) participants, conducted at Life Esidimeni Intermediate Care (LEIC) and Booth Memorial Hospital (BMH) respectively; using the FGD interview guide described above in Chapter 2, section 2.4.1, in the format of an in-depth, open-ended, and structured interview, conducted by the researcher and a trained research assistant, at a time that was convenient for the participants. The research aims and objectives were discussed with the research assistant. The first interviews with the healthcare professionals and patients with stroke were conducted by the researcher while the research assistant observed.

Babie et al. (2001) described that a FGD allows individuals in the group to create meaning about a certain concept, while considering the opinions of others. Krueger et al. (2015) highlighted five characteristics or 'ingredients' of a focus group, including: a small group of people, who possess certain characteristics, provide qualitative data, in a focused discussion, so as to help understand the topic. According to Krueger, a number of principles should be adhered to when facilitating a FGD, including: observing the traditional recommended size for a FGD of between five and eight participants, so as to allow each individual the opportunity to share their insights and perspectives; discussions taking place in an allocated venue that is quiet and

comfortable; and finally, the fact that participants should be seated in a circle to facilitate discussions (Krueger, 2002). McMillan et al. (2014) highlighted that FGD can generate more ideas than a single interview, but dominant personalities can influence the discussions, and ideas are not always prioritized. Krueger et al. (2015) agreed with this criticism but explained that this risk can be minimized and managed appropriately with a skilful moderator.

Saturation of the focus groups was considered by the researcher as part of the data collection process of this study. Mason (2010) noted that if a researcher remains faithful to the principles of qualitative research, sample size in the majority of qualitative studies should generally follow the concept of saturation, whereby the collection of new data does not shed any further light on the issue under investigation. Hancock et al. (2016) indicating that data saturation can be reviewed three ways, by group, individual, or study day. Through the focus group discussions, exhaustion of the questions demonstration by repetition of responses by the participants illustrated saturation.

2.5.2 Phase 3

The data collection method for Phase 3 of this study was through the implementation of in-depth, semi-structured, one-on-one interviews, using the interview guide described above in Chapter 2, section 2.4.2.

Interviews, as explained by Fontana et al. (2005), are a widely used tool to access people's experiences and their inner perceptions, attitudes, and feelings of reality; and that based on the degree of structuring, interviews can be divided into three categories: structured interviews, semi-structured interviews, and unstructured interviews. Zhang et al. (2009) reported on the various structures, indicating that a structured interview is one in which the interview has a set of organized questions that would be asked in the same order for all participants; and that the standardization is done lessen the effects of the instrument and the interviewer on the results. In addition, semi-structured interviews, as the name implies, are more flexible; whereby the interview guide is prepared; but during the course of the interview, the interviewer has a certain amount of room to adjust the sequence of the questions to be asked, and to add questions based on the context of the participants' responses (Zhang et al., 2009).

2.5.3 Phase 4

The data collection method for Phase 4 of this study was through the implementation of a document review process; whereby the researcher requested that the 'expert panel' review and comment on the draft South African Bridges stroke SMI workbook. After reviewing the draft, the experts documented their responses electronically to the researcher. The Department of Health and Human Services (2009) confirmed this data collection method, noting that, 'document review' is a way of collecting data by reviewing existing documents, either through review of a hard copy or electronic copy. Furthermore, the advantages of this method of data collection are that it is inexpensive to undertake; provides a good source of information; is unobtrusive; provides a behind-the-scenes look at the programme that may not be directly observable; and, may bring up issues not noted by other means (Department of Health and Human Services, 2009). Figure 2.3 below summarizes the data collection methods used throughout the study.

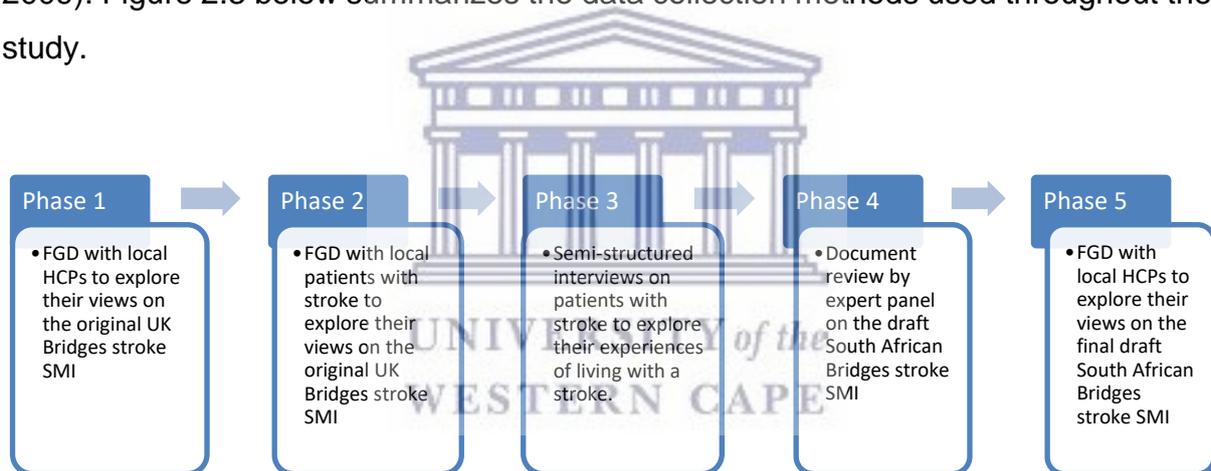


Figure 2.3: Data collection methods used throughout the study

2.6 DATA ANALYSIS

Audio recorded data obtained from the focus group discussions and interviews were transcribed verbatim by an independent transcriber, who is fluent in the language of the discussions, for analysis of common themes. According to Daly et al. (1997), themes are identified as patterns across various data sets that are important to the description of a phenomenon and are associated to a specific research question. Braun et al. (2006, p.10) concurred, highlighting that "a theme captures something

important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set”.

Throughout the various study phases, a thematic analysis procedure is employed by the researcher to analyse and interpret the themes identified through the qualitative data collected. A deductive approach was employed by the researcher for the focus group discussion data of Phase 1, 2, and 5; and an inductive approach to the data from the interviews in Phase 3.

Braun et al. (2006, p.12) cited literature explaining that themes “can be identified in one of two primary ways in thematic analysis: in an inductive way (Frith et al., 2004), or in a deductive way (Boyatzis, 1998; Hayes, 1997). Braun et al. (2006, p.4) reported that thematic analysis is “a method for identifying, analysing, and reporting patterns (themes) within data”; is “a poorly demarcated, rarely acknowledged, yet widely used qualitative analytic method that offers an accessible and theoretically flexible approach to analysing qualitative data”; and, “involves the searching across a data set, be that a number of interviews or focus groups, to find repeated patterns of meaning”.

Furthermore, Braun et al. (2006, p.12) explained that, “an inductive approach means the themes identified are strongly linked to the data themselves. Inductive analysis is therefore a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher’s analytic preconceptions. In this sense, this form of thematic analysis is data driven”. A deductive approach to analysis of the data, according to Braun et al. (2006, p.12) “would tend to be driven by the researcher’s theoretical or analytic interest in the area and is thus more explicitly analyst-driven. This form of thematic analysis tends to provide less a rich description of the data overall, and more a detailed analysis of some aspect of the data”.

Thematic analysis, according to Braun et al. (2006) is performed through the process of coding six phases to create established, meaningful patterns. These phases include: familiarization with data, generating initial codes, searching for themes among the codes, reviewing themes, defining and naming themes, and producing the final report. During the first phase, when becoming familiar with the data it is important to become fully immersed to the extent that one is familiar with the depth and breadth of the content. This immersion usually involves repeated reading of the data and reading

the data in an active way so as to search for meanings and patterns. The second phase, generating initial codes, involves the production of initial codes from the data that appears interesting to the analyst, and refers to the most basic components of the raw data or information that can be assessed for meaning. In the third phase, searching for themes, analysis is focused at the broader level of themes, rather than codes; and involves sorting the different codes into potential themes through collation of all the relevant coded data extracts within the identified themes. The fourth phase, reviewing themes, begins when a set of candidate themes have been developed; and involves the refinement of those themes. The fifth phase, defining and naming themes, begins when a satisfactory thematic map of the data is available. At this point, the themes that will be presented for analysis are defined and further refined for analysis of the data within them. Finally, producing the report, begins when a set of fully worked-out themes are available, and involves the final analysis and write-up of the findings. The researcher endeavoured to follow these six phases of data analysis, as laid out by Braun et al. (2006), throughout this study.

Ritchie et al. (2013) explained that our location within a broadly interpretivist frame is reflected in practices, which emphasizes the importance of understanding people's perspectives in the context of the conditions and circumstances of their lives. This has implications both for the balance between inductive and deductive approaches across the research process; and for the ways in which we analyse and develop interpretations of the data. Whatever existing theories and research that is brought forward into studies, there is a strong requirement for interpretation to be heavily grounded in and supported by the data. As far as possible, the aim needs to be on mapping the full range of opinions and experiences of participants, based initially on their own accounts. Where interpretations move beyond the explicit descriptions and accounts provided by individual participants, great importance is placed on ensuring that it is clear how more abstract interpretations relate to the data provided by study participants (Ritchie et al., 2013).

2.7 TRUSTWORTHINESS

Agostinho (2004, p.8) highlighted that "the benchmarks of rigor for conventional scientific inquiry, being: internal and external validity, reliability, and objectivity, are all based on the ontological belief of scientific realism". Creswell (2013) has provided

eight verification procedures and recommended that a qualitative researcher engage in at least two of them in a research study. His suggested procedures encompass the trustworthiness criteria presented by Lincoln and Guba (1985). Trustworthiness in this study was established based on the framework, first presented by Lincoln and Guba (1985), and used in qualitative research since, as confirmed by Shenton (2004). The trustworthiness criteria of credibility (ensuring that the study measures what it intends to measure); transferability (the consideration of applying the findings of the study to other settings); confirmability (ensuring that the findings of the study are based on the experiences, views and opinions of the participants and not that of the researcher); and dependability (if the work were repeated, in the same context, with the same methods and with the same participants, similar results would be obtained) were achieved in this study. The following provisions were made by the researcher, at various appropriate stages of the study, to promote confidence that the phenomena have been accurately recorded:

2.7.1 Credibility

Shenton (2004, p.64) explained that the notion of “internal validity seeks to ensure that research measures or tests what is actually intended; and credibility, deals with the question, “How congruent are the findings with reality?” Lincoln and Guba (1985) argued that ensuring credibility in research is one of the most important factors when establishing trustworthiness.

- ‘Adoption of well-established research methods’

As described by Shenton (2004), the researcher endeavoured to employ specific procedures in this study based on previous successful and comparable studies; in this case Hale et al. (2014), through use of a similar protocol, line of questioning, and data gathering and analysis procedures.

- ‘Development of early familiarity with culture of participating organizations’

Shenton (2004) emphasized the importance of consulting appropriate documentation and conducting preliminary visits to organizations involved in the study prior to data collection. In this case, the researcher attended the Bridges Head Office in the United Kingdom for a period of two weeks to become more familiarized with the concept,

content and course material of the Bridges SMP and SMI workbook. Further to this, “prolonged engagement” was demonstrated in this study as the researcher was involved as both an active participant and observer for the entire duration of the study with all stakeholders.

- ‘Triangulation’

Gray (2014) noted that, in practice, it is often the case that multiple methods, or a mixed approach, will be used in a qualitative study. One reason for using multiple methods is that it enables triangulation to be used. Data triangulation, as identified by Gray (2014), is the collecting of data over different times or from different sources. This approach is typical of cross-sectional designs, such as in this study. Methodological triangulation is also possible, with the use of a combination of methods, such as: researcher observation, focus group discussions, interviews and review of transcripts for the purpose of data collection; as is also the case in this study. Further triangulation during data collection was achieved through use of various data sources and site triangulation; whereby more than one research site was employed, and viewpoints and experiences of users and healthcare professionals were collected.

During data analysis, different types of data sets were used to refine and substantiate emergent themes, such as transcripts being triangulated with the field notes and researcher observations. Different data analysis techniques were also employed, through use of an inductive thematic analysis approach, complimented with a deductive approach, which resulted in a high degree of convergence. Gray (2014) explained that all methods have their strengths and weaknesses; not only does the use of multiple methods assist in data triangulation, it helps to balance out any of the potential weaknesses in each data collection method.

- ‘Tactics to help ensure honesty in informants’

The researcher followed the guidelines of Shenton (2004) and providing each participant with the opportunity to refuse to participate in the study when they were issued with the information sheet and consent form. Furthermore, in the information sheet, it was made clear to all participants that they had a right to withdraw from the study at any point without question.

- 'Negative case analysis'

Negative case analysis was applied by the researcher during data analysis to refine the clustering of themes into categories; as highlighted by Shenton (2004) who indicated that the investigator may revisit the data in order to confirm that these constructs do indeed account for all instances of the phenomenon involved.

- 'Frequent debriefing sessions'

As described by Shenton (2004), the researcher held frequent debriefing sessions with his supervisors to produce and refine the research vision and methodological processes, adapt approaches, and monitor progress of the study. The sessions also allowed for the researcher to gain experience and widen perceptions of the topic and qualitative research process.

- 'Peer scrutiny of the research project'

Debriefing and scrutiny of the research study were welcomed by the researcher, as highlighted by Shenton (2004), through formal discussions with the research supervisor and co-researcher, as well as local and international rehabilitation healthcare professionals with intimate knowledge of the self-management intervention and the Bridges SMP, such as the Bridges SMP founder, and New Zealand Bridges principle researcher in particular, who provided expertise, guidance, and direction to the study.

- 'Member checks'

According to Shenton (2004), member checks are considered one of the most important provisions that can be made to strengthen the credibility of any study. In this study, the researcher achieved member checking both informally, during the data collection phases of this study, and formally, after data collection was completed. In the case of informal member checks, data was confirmed by the researcher with the participants on the spot during the data collection, to confirm that what was being said was in fact correctly understood. In the case of formal member checks, the researcher made transcripts of the recorded data and reviewed it with the participants to ensure

what was said and transcribed was in actual fact what the participants meant to say on the topic in question.

- ‘Thick description of phenomenon under scrutiny’

Shenton (2004, p.69) reported that “detailed description in this area can be an important provision for promoting credibility as it helps to convey the actual situations that have been investigated and, to an extent, the contexts that surround them”. The researcher attempted to detail the study as comprehensively as possible, to ensure the reader is able to make a determination of whether or not the findings ring true.

- ‘Examination of previous research findings’

The researcher examined the only available comparable study, conducted by Hale et al. (2014), to assess the congruency of the results achieved (Shenton, 2004).

2.7.2 Transferability

The notion of ‘external validity’ is described by Merriam (1995) as being focused on the degree to which the findings of one study can be applied to others. Shenton (2004) however, questioned whether the notion of producing truly transferable results from a single study is a realistic aim, or whether it disregards the importance of context, which forms such a key factor in qualitative research. However, Shenton (2004) stressed the importance of researchers conveying the study’s background information to the reader; with the following information being required from the outset:

- o the number of organizations taking part in the study and where they are based;
- o any restrictions in the type of people who contributed data;
- o the number of participants involved in the fieldwork;
- o the data collection methods that were employed;
- o the number and length of the data collection sessions;
- o the time period over which the data was collected.

- ‘Provision of study background information’

The researcher provided detailed descriptions of phenomenon in question; as well as comprehensive information on the number of organizations taking part in the study;

the characteristics and number of the participants involved; the data collection procedures; and finally, comprehensive information on the data collection sessions to assist the reader to establish context of the study and allow comparisons to be made.

2.7.3 Dependability

Shenton (2004, p.71) explained that the issue of reliability is one where, “if the work were repeated, in the same context, with the same methods, and with the same participants, similar results would be obtained”.

- Employment of “overlapping methods”

Lincoln and Guba (1985) stress the close ties between credibility and dependability; arguing that, in practice, demonstration of credibility ensures dependability. Shenton (2004) highlighted that this could therefore be achieved through the implementation of ‘overlapping methods’, which the researcher in this study employed through the use of both focus group discussions and interviews of participants.

- Comprehensive methodological description

Shenton (2004, p.71-72) concluded that, to address the issue of dependability more effectively, the processes within the study should be reported comprehensively, “thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results”. The following information was proposed to be included:

- o ‘Research design and implementation’
- o ‘Operational detail of data gathering’
- o ‘Reflective appraisal of the project’

As eluded to previously, the researcher in this study endeavoured to provide comprehensive descriptions of the methodological processes followed, including the research design and implementation strategy; and operational details of data gathering methods, so as to assist the reader to develop a thorough understanding of the methods and their effectiveness.

2.7.4 Confirmability

The concept of 'confirmability', as described by Shenton (2004, p.72), is concerned with the notion of objectivity; whereby "steps must be taken to help ensure, as far as possible, that the findings of the study are the result of the experiences and ideas of informants, rather than the characteristics and preferences of the researcher".

- Triangulation to reduce effect of investigator bias

Shenton (2004) explained that beliefs underlying the researcher's decision making and methods employed during the study should be acknowledged in the research report; adding explanations for adopting one approach over another and highlighting weakness in the techniques implemented. The researcher attempted to make clear the reasons for decisions made during the research process; and highlighted the study's weaknesses under 'Limitations of the study' in Chapter 6, section 6.4.

- Use of diagrams to demonstrate "audit trail"

Audit trails, according to Shenton (2004, p.72), "allow observers to trace the course of the research step-by-step via the decisions made and procedures described" and can be depicted through 'data-orientated' or 'theoretical' approaches. Accessibility to an audit trail was achieved by the researcher, according to Lincoln and Guba's (1985) six categories of information: 1) raw data, such as: written field notes and audio recordings; 2) data reduction and analysis products, such as: summaries, theme identification, and working hypotheses; 3) data reconstruction and synthesis products, such as: clustering of themes into categories, interpretations, and the final report; 4) process notes, such as: methodological notes and trustworthiness notes; 5) information about intentions and disposition, such as: the research proposal and personal notes; and 6) instrument development information, such as: focus group discussion interview guide design and that of the semi-structured interview questions.

In summary, according to the above information, the researcher asserts that this study represented a good quality qualitative research study; as the research design was congruent with the research focus, enabling flexibility and permitting the issues to unfold in a naturalistic setting; as well as the fact that rigor was achieved through the establishment of trustworthiness and authenticity. The trustworthiness criteria of

credibility, transferability, dependability, and confirmability were established in this study and appropriately met.

2.8 ETHICAL CONSIDERATIONS

Brown (2006) reported that ethical behaviour in research isn't complicated, and that the researchers should avoid actions or questions that can be viewed as threats to the participants' health, values or dignity.

Ethical clearance and permission to conduct this study was obtained from the University of the Western Cape Ethics Committee, University of the Western Cape Senate Research Committee, from the Western Cape Department of Health; and finally, for recruitment of participants, permission was received from the LEIC and BMH in order to get a referral sample pool. Confidentiality of all participants, whether included or excluded from the study, was ensured by not disclosing any information to unauthorized parties. The use of password-protected computerized files, as well as identification coding on information gathered, was used for all data obtained. The participant's name was not included on the collected data. A code was placed on the research instruments and other collected data, through the use of an identification key, which only the researcher was able to link relevant information to the participant's identity; and only the researcher had access to the identification key. All included participants received full disclosure regarding the aims, objectives and purpose of the research study through the use of comprehensive information sheets. Written informed consent was obtained from each of the participants, or the participant's guardian, to use the information and photos obtained for purposes of inclusion in the workbook. All participants were given the option of using pseudonyms in the workbook for the purpose of maintaining the confidentiality of their true identity. All participants were given the right to refuse participation in the study without question. Participants in the study were afforded the right to, at any point in time, withdraw from the study without repercussions (refusal of further treatment or stigmatisation from the therapists/community). Counselling was provided for any participant who required, only as it was requested. Results of the study were made available to the relevant parties upon completion. Any necessary referrals for participants or family members were handled as the need arose.

CHAPTER THREE

VIEWS ON THE IMPLEMENTATION OF THE BRIDGES STROKE SMI

3.0 INTRODUCTION

This chapter describes the first two phases of the study, which unpack the first two objectives, being: 'To explore healthcare professionals' views on the implementation of the original UK Bridges stroke SMI workbook for the South African context'; and, 'To explore the views that South African patients with stroke have of the original UK Bridges stroke SMI workbook'. The chapter first explores the 'Background' of the objectives; then contains a brief 'Methodology' of the processes followed; the 'Results' obtained during these processes; the subsequent 'Discussion'; and finally, the chapter ends with the 'Summary' of the overall findings.

3.1 BACKGROUND

The International Alliance of Patients' Organisations (IAPO, 2012) highlighted that health services were originally organized to respond to and treat acute illness; but that in today's age, are more and more challenged to respond to the care and treatment of chronic diseases, such as cerebrovascular diseases, due to their high morbidity and mortality rates. This development however brought about a need for a fundamental shift in health systems and healthcare; and, as a consequence, a shift in the subsequent roles and responsibilities of patients. IAPO (2012) explained further that, in line with this health transition, the focus on the patient's role in managing their own health has grown substantially and is an increasing focus of health policy. With this, has come a shift towards care and treatment moving out of the acute hospital environment and into the community and home environment; leaving patients and family with a greater need for involvement in their own healthcare management.

As highlighted by Boger et al. (2012) in Chapter 1.1.5, engagement with self-management programmes (SMP) by patients with long-term chronic conditions, such as stroke, has been identified to be the key to promoting recovery, empowering the individual, and facilitating improved health outcomes. However, an SMP delivered by

healthcare professionals as part of the routine or usual stroke rehabilitation has potential cost and time implications, especially when utilizing an individualized approach; a feasibility study conducted by Jones et al. (2016) found that it was in fact feasible to integrate both 'usual' rehabilitation and the SMP approach. Although delivery of a SMP is feasible in the context of integration into usual rehabilitation; Perrin et al. (2006) stressed that maintaining fidelity of the SMP is crucial for its success.

With this in mind, 'implementation fidelity', was described by Carroll et al. (2007, p.1) as, "The degree to which an intervention or programme is delivered as intended", becomes an important factor for researchers to consider when replicating SMPs (Perrin et al., 2006). Perrin et al. (2006) observed that, due to the high prevalence of chronic diseases and associated health disparities, there is a greater need for SMPs that improve health behaviours and health status; therefore, in an effort to meet this need and expand such programmes, healthcare providers often attempt to replicate successful self-management interventions (SMIs) with populations that are different from the population originally used in the successful SMP trials or studies. Programmes that display perfect fidelity to the original trial but are without a conceptual framework for adapting to different diseases, treatments, patients, providers, institutions, and cultures can be unrealistic in real-world clinical practice (Perrin et al., 2006).

The nature of the Bridges SMP is that it can be adapted and contextualized to meet the specific need of the population in question, as highlighted successfully by Hale et al. (2014) when adapting and contextualizing the UK Bridges stroke SMI for the New Zealand stroke population. Conde et al. (2005) highlighted that, during the adaptation process of programmes, relevant stakeholders are both central and fundamental, as it is they who comprise the 'adaptation community' and who are required to sustain the process. The Agency for Healthcare Research and Quality (AHRQ, 2014) described 'stakeholders' as, persons or groups that have a vested interest in a clinical decision; and the evidence that supports that decision. Stakeholders, at different levels and stages, are crucial to the success of an adaptation project. A point concurred by Mchunu (2010), who indicated further that it is essential to identify the key role players who would be impacted by the changes, and their level of influence to enable change. Conde et al. (2005) underscored that through listening to the views of others,

stakeholders can build a shared understanding of the issues. Out of the stakeholder discussions, priority areas for action can emerge that take account of everyone's perceptions. There are many benefits of stakeholder engagement. For one, participatory initiatives are more likely to be sustainable because they build on local capacity and knowledge, resulting in participants taking ownership and responsibility for any decisions made. Furthermore, working closely with local communities through stakeholder engagement can help decision-makers gain greater insight into the communities they serve, enabling them to work more effectively and produce better results. In this way, it increases people's potential for reducing their vulnerability; which, in turn, empowers people and enables them to tackle other challenges, individually and collectively. Finally, stakeholder participation in planning, through priority-setting and voicing preferences, as well as in implementation, is in line with promoting people's right to participate in decisions that affect their lives (Conde et al., 2005).

Engaging with various stakeholders can offer unique perspectives; and involving them from the beginning of the research can improve research results; help to ensure that findings are relevant to users' distinct concerns; and have applications in real-world situations. Healthcare professionals, and their professional associations, are at the heart of medical decision making. Once the research is produced, stakeholders who were involved in the process are more likely to actively use and disseminate the information that they helped produce (AHRQ, 2014). Healthcare professionals are the main stakeholders responsible for delivering and integrating the Bridges SMP and stroke SMI workbook into the routine stroke rehabilitation or 'usual care' experienced by patients with stroke (Jones et al., 2016); and therefore, their buy-in to the SMP is critical for its success in any context.

Patients however are the ultimate stakeholders of clinical research, explains Tunis et al. (2002). A habit ingrained in many organizations and infrastructures is to give patients information, but not enter into an interactive and respectful dialogue to understand their views on matters that directly concern them. All decisions about plans, structures, and programmes, should involve patients from the very beginning. If the patients are not involved up front, they will be involved at a later stage, but perhaps in ways that are not the most effective or appropriate (Tunis et al., 2002).

AHRQ (2014) emphasized that it is vital that research engages with consumers, patients, and caregivers, to understand, and answer, the questions of greatest importance to those experiencing the situation that the research aims to address. Oliver et al. (2004, p.6-7) stressed that consumers should be involved because their experience and insights can complement those of healthcare professionals and researchers; so that collectively 'better' research can be produced, which may: "have a higher methodological or ethical quality"; "produce findings which are more relevant to practical decision making by consumers (patients) and those caring for them"; "allow for more accessible and widely disseminated reports"; or, "more appropriately influence policy and practice".

The importance of understanding the relevance and acceptability of the Bridges SMP and stroke SMI in the local context, through the views of local healthcare professionals and patients with stroke, is therefore of vital importance. Hale et al. (2014) recognized the crucial importance of this in their research by engaging and consulting with neurorehabilitation healthcare professionals in their first phase, and patients with stroke in their second phase; to better understand their views and the potential requirements for adaptation and contextualization of the workbook to their specific context. In this way, as part of the conceptual framework underlining this research, the researcher in this study also engaged with the healthcare professionals and patients with stroke in Phase 1 and 2 respectively to better understand their perceptions and views on the implementation of the Bridges SMP and stroke SMI workbook.

3.2 METHODOLOGY

3.2.1 Study Population and Sampling

3.2.1.1 Phase 1 – Healthcare professionals

Convenience sampling was employed for recruiting healthcare professionals (HCP) as participants into the study during Phase 1 (Suen et al., 2014). All available members of the multi-disciplinary rehabilitation team responsible for the rehabilitation of patients with stroke at both Life Esidimeni Intermediate Care (LEIC) and Booth Memorial Hospital (BMH) were approached to be conveniently selected to participate in the study. The HCP participants from LEIC included in the study consisted of eight participants, comprising: two Physiotherapists, two Occupational Therapists, a Social

Worker, a Speech and Language Therapist, a Dietician, and a Registered Nurse; while the HCP participants from BMH consisted of five participants, comprising: one Physiotherapist, one Occupational Therapist, a Social Worker, and two Registered Nurses. In total, for the first phase of this study, 13 healthcare professionals were included. Table 3.1 below depicts the designations of the HCP participants across the two facilities.

Table 3.1: Designation of Phase 1 participants

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

3.2.1.2 Phase 2 – Patients with stroke

Purposive sampling of patients with stroke was implemented to recruit participants into the second phase of the study (Suen et al., 2014). The participants were selected by the researcher, from a list of patients with stroke compiled by the chief therapists of LEIC and BMH respectively as seen below in Chapter 3, section 3.2.3.2, based on their gender, ethnicity, age, diagnosis, and level of mobility. Each potential participant was screened prior to inclusion as participants into the study, using the inclusion criteria described in Chapter 2, section 2.3.2, with a focus on encouraging cultural diversity amongst the selected participants for the focus group discussions.

Twelve patients with stroke were included as participants in this phase of the study; with the demographic spread as follows: Seven male and five female participants; eight coloured and four black participants; ages ranging from the lowest being 49 years of age, to the oldest being 70 years of age; with an equal spread of six left and six right CVA clinical diagnoses. The participant's clinical presentations included: five who were independently mobile; three who were independently mobile with assistive devices (walking frame, quadrupod, and elbow crutches respectively); one who required assistance with mobility and an assistive device (quadrupod); and three who were still wheelchair dependent. All participants exhibited some degree of unilateral hemiplegia on either their left or right side; while other participants exhibited speech and language impairments of dysarthria and word finding difficulties. Table 3.2 below depicts the socio-demographic data, including the gender, ethnicity, age, diagnosis, and level of mobility of the participants included in the focus group discussions of Phase 2.

Table 3.2: Socio-demographics of Phase 2 participants

Participant	Gender	Ethnicity	Age	Diagnosis	Level of Mobility
1.	M	C	52	Left CVA	Assistance with wheelchair
2.	M	C	54	Right CVA	Assistance with quadrupod
3.	M	B	51	Left CVA	Independent in wheelchair
4.	F	B	52	Right CVA	Independent mobility
5.	F	B	65	Left CVA	Assistance with wheelchair
6.	F	B	54	Right CVA	Independent mobility
7.	M	C	49	Left CVA	Independent mobility
8.	F	C	62	Left CVA	Independent with walking frame
9.	F	C	56	Right CVA	Independent mobility
10.	M	C	54	Right CVA	Independent with quadrupod
11.	M	C	70	Right CVA	Independent with elbow crutches
12.	M	C	69	Left CVA	Independent mobility

3.2.2 Research Instrument

The research instrument employed for Phase 1 and 2 of this study was that of a focus group discussion interview guide, made up of 12 questions. As mentioned in Chapter 2, section 2.4.1 (Annexure M), the following questions were asked: 1) “How did you find the general layout of the workbook?”; and, 2) “How practical is the workbook in its design and feel?”. This was followed up by six questions as they relate to the content of the workbook, namely: 3) “What did you think of the overall content of the workbook?”; 4) “How appropriate and applicable were the stories to you?”; 5) “What stories stood out as being the most appropriate for you?”; 6) “What stories stood out as being the most inappropriate for you?”; 7) “How appropriate and applicable were the pictures to you?”; and, 8) “What would you change in the workbook?”. The researcher then proceeded to ask three questions about the user-friendliness of the workbook, namely: 9) “How did you find the overall user-friendliness of the workbook?”; 10) “Were you able to navigate or find the section or chapter you were looking for?”; and, 11) “Were you able to understand the flow of each section?”. The FGD interview guide concluded with the final question, 12) “What are your views on the implementation of this SMI in our local context?”.

3.2.3 Data Collection Procedure

3.2.3.1 Phase 1 – Healthcare Professionals

After receiving the appropriate ethical clearance from the University of the Western Cape Ethics Committee, and permission from Life Esidimeni Intermediate Care (LEIC) and Booth Memorial Hospital (BMH) respectively; the researcher requested to present the study proposal at a staff meeting held separately at the individual institutions. The researcher then verbally invited the HCPs who attended these two meetings to participate in the study. Each participant was first presented with an information sheet, in the language of their preference (Annexures A, B, C) from the researcher, which detailed their specific involvement in the study. Thereafter, the purpose of the study was comprehensively explained to them by the researcher; and informed consent, in the language of their preference (Annexures H, I, J), was then requested. The participants were then issued with a copy of the original Bridges stroke SMI workbook to review for two weeks. The researcher gave instruction to the participants to review

the workbook with the four main areas that was under investigation in mind, namely: “General Workbook Layout”, “Workbook Content”, “Workbook User-Friendliness”, and “Implementation of the SMI in South African Context”.

The HCP participants were then invited to participate in a focus group discussion (FGD) that occurred two weeks after they had been issued with the workbook. A total of 13 HCP participants were recruited across the two focus groups in the first phase; with eight participants in the FGD at LEIC, and five participants in the second FGD at BMH. The two FGDs with the HCP participants were conducted in English, separately at LEIC and BMH respectively, using the FGD interview guide (Annexure M), and conducted by the researcher and a trained research assistant, at a time that was convenient for the participants. Both FGD took place according to the recommendations of Krueger et al. (2015) and Krueger (2002). Prior to the start of the FGD, the participants were requested to sign a ‘focus group binding form’ (Annexures K, L), whereby the participants committed that the information discussed in the focus group would be kept confidential and would not be discussed outside of the focus group. Each FGD took approximately 30 minutes to complete.

3.2.3.2 Phase 2 – Patients with Stroke

The chief therapists of LEIC and BMH respectively, who were made aware of the study when the researcher presented it at the specific staff meetings prior to Phase 1, were approached for a list of names of possible patients with stroke who could potential be included as participants in the FGD. The inclusion criteria were shared with the chief therapists; and participants were recruited from a list of patients with stroke who were in-patients, and would still be in-patients, at the two institutions at the time of the data collection points. Once the list of 12 names had been received, the researcher did a final screening, per the inclusion criteria described in Chapter 2, section 2.3.2; and purposively selected all 12 of the participants based on their characteristics and cultural diversity to ensure the feedback received was as representative of the available stroke populations as possible. Selected participants were approached and verbally invited to be part of the study. Those who agreed were first presented with an information sheet from the researcher, in the language of their preference (Annexures D, E, F), which detailed their specific involvement in the study. Thereafter, the purpose of the study was comprehensively explained to them by the researcher; and informed

consent was then requested, in the language of their preference (Annexures H, I, J). All participants in the study were able to provide informed consent themselves. Thereafter, the participants were issued with a copy of the original Bridges stroke SMI workbook to review for two weeks. All participants were able to read and understand English. As with Phase 1, the researcher gave instructions to the participants to review the workbook with the four main areas, that were under investigation, in mind, namely: “General Workbook Layout”, “Workbook Content”, “Workbook User-Friendliness”, and “Implementation of the SMI in the South African Context”.

The participants were then invited to participate in a FGD that occurred two weeks after they had been issued with the workbook. A total of 12 participants were recruited across the two focus groups; with six participants in the first FGD, and six in the second. All 12 participants, who were issued the workbook to review, participated in the FGDs. The two separate FGDs were conducted in English by the researcher, at LEIC and BMH respectively, over two different time periods. As with the first phase, the FGD interview guide was used as a guide, conducted by the researcher, at a time that was convenient for the participants. Both FGD took place according to the recommendations of Krueger et al. (2015) and Krueger (2002), to ensure comprehensive and accurate feedback from the participants on their views regarding the implementation of the original Bridges stroke SMI workbook in the local South African setting. Prior to the start of the FGD, the participants were requested to sign a ‘focus group binding form’ (Annexures K, L), whereby the participants committed that the information discussed in the focus group would be kept confidential and would not be discussed outside of the focus group. Each FGD took approximately 30 minutes to complete.

3.2.4 Data Analysis

The qualitative data from the FGDs in Phase 1 and 2 was collected via an audio recording device, used by the researcher and trained research assistant; as well as field notes that were taken during the discussions. Transcripts were made of the audio recordings. To prevent bias from occurring during data collection throughout all phases of this study, the FGDs and transcriptions were done by two different individuals. The audio recorded data was transcribed verbatim by an independent transcriber, who is fluent in English and Afrikaans, the two languages used by the participants during the

FGD, for analysis of common themes. A summary of the transcripts was then shared with the participants during a follow-up visit, as part of the formal member-checking process described in Chapter 2, section 2.7.1. The HCP and patient with stroke participants were able to read and understand the transcripts; and were all in agreement that the transcripts were an accurate reflection of the discussions held. For Phase 1 and 2 of the study, a deductive thematic analysis procedure, as described by Braun et al. (2006) in Chapter 2, section 2.6, was employed to analyse the qualitative data collected. A deductive approach to analysis of the data, according to Braun et al. (2006, p.12) “would tend to be driven by the researcher’s theoretical or analytic interest in the area and is thus more explicitly analyst-driven. This form of thematic analysis tends to provide less a rich description of the data overall, and more a detailed analysis of some aspect of the data”.

Trustworthiness of the data obtained in Phase 1 and 2, was achieved by ensuring that the standards of credibility, transferability, dependability and conformability were met as described by Shenton (2004) in Chapter 2, section 2.7. Credibility was attained by making it clear to participants that their participation was voluntary, and that they had the right not to participate, thus the use of informed consent forms. Further credibility was obtained through the use of verbal probes, by the researcher, during the focus group discussion to get the required data from participants so that the research question was answered. Finally, credibility was achieved through the use of member checking; done informally, as well as formally as previously described. Transferability and dependability were obtained through detailed provision of information about the study under investigation, including a comprehensive methodology and adequate information regarding fieldwork sites. Lastly confirmability was obtained by the researcher keeping an audit trail of the processes followed; making it possible to trace the course of the research step by step through the decisions made and procedures described.

Reflexivity, the seventh characteristic of good qualitative research, as described by Cresswell (2013) in Chapter 2, section 2.2.1, is described by the researcher below; whereby background information provided on the researcher allows the reader to have a more complete picture of the approach to the study. The researcher is a physiotherapist by profession; graduating from the University of the Western Cape in

2009. Research, in particular as it relates to neurological rehabilitation, is a special interest to the researcher; who conducted a Master's dissertation titled: "The Factors Influencing Functional Outcomes of Stroke Patients Receiving Rehabilitation at a Sub-acute Rehabilitation Facility in the Western Cape". Looking to enhance the quality of clinical rehabilitation techniques used by healthcare professionals for patients living with stroke in the local communities to address participation restrictions; the researcher searched for a clinical programme guide that could address this area of concern. The Bridges SMP and SMI workbook was identified. To maintain implementation fidelity, as described above in Chapter 3, section 3.1, of the Bridges stroke SMI workbook when adapting the SMI for the South African context, and to better understand the context in which the SMI was originally developed for, the researcher of this study spent two weeks in the UK at the Bridges Head Office, with the Bridges programme founder and current coordinators. During the two-week period, the researcher was exposed to the Bridges organization as a social enterprise, the staff involved in the coordination and facilitation of the Bridges SMP, and the healthcare professional SMP training workshops that are delivered by Bridges. The researcher attended two such workshops, one at the start of the two weeks and one at the end; and gained tremendous insight into the organization, the SMP and SMI in the context that it was developed for; and also, how best to approach the adaptation and contextualization process of the SMP for the South African context.

3.2.4 Ethical Considerations

Ethical considerations were applied throughout as indicated in Chapter 2, section 2.8; with the following considerations for this phase: for recruitment of participants, permission was requested and received from LEIC and BMH in order to get a referral sample pool. Confidentiality of all participants, whether included or excluded from the study, was ensured by not disclosing any information to unauthorized parties. The use of password-protected computerized files, as well as identification coding on information gathered, was used for all data obtained. The participant's name was not included on the collected data. A code was placed on the research instruments and other collected data, through the use of an identification key, which only the researcher was able to link relevant information to the participant's identity; and only the researcher had access to the identification key. All included participants received full

disclosure regarding the aims, objectives and purpose of the research study through the use of comprehensive information sheets. Written informed consent was obtained from each of the participants, or the participant's guardian, to use the information and photos obtained for purposes of inclusion in the workbook. All participants were given the right to refuse participation in the study without question. Participants in the study were afforded the right to, at any point in time, withdraw from the study without repercussions (refusal of further treatment or stigmatisation from the therapists/community). Counselling was provided for any participant who required, only as it was requested.

3.3 RESULTS

The qualitative data obtained through the FGDs held with the HCP and patients with stroke participants in Phase 1 and 2, focused on their views as they relate to the implementation of the original Bridges stroke SMI workbook in the local setting; and is presented below according to the themes highlighted in the four main categories of the discussion, namely: "General Workbook Layout", "Workbook Content", "Workbook User-Friendliness", and "Implementation of the SMI in the South African Context". Refer to Table 1 and 2 above in Chapter 3.2.2 for the description of the HCP and patients with stroke participants. Table 3.3 below depicts the 16 overall themes to be presented and discussed throughout the remainder of this chapter, including the theme category, theme number and theme name.

Table 3.3: Themes identified during FGDs in Phase 1 and 2

Theme Category	Theme Number	Theme Name
General Workbook Layout	Theme 1	Content Structure
	Theme 2	Colour scheme
	Theme 3	Sequence of information
	Theme 4	Workbook binding
	Theme 5	Orientation of the workbook
Workbook Content	Theme 1	Variety of vignettes
	Theme 2	Young stroke
	Theme 3	Content appropriateness
	Theme 4	Picture appropriateness

	Theme 5	Stroke Education
Workbook User-Friendliness	Theme 1	Language implementation
	Theme 2	Navigation tabs
	Theme 3	Location of vignettes
Implementation of the SMI in the South African Context	Theme 1	Benefits of the SMI
	Theme 2	HCP SMI training
	Theme 3	Barriers to implementation

3.3.1 General Workbook Layout

Within this category, five main themes arise that are highlighted by the HCP and patients with stroke participants respectively. The first theme identified and presented focuses on the ‘Content structure’ of the original Bridges stroke SMI workbook; the second theme involves the ‘Colour scheme’ of the workbook; the third theme identified relates to the ‘Sequencing of information’ of the chapters within the workbook; the fourth theme relates to the ‘Workbook binding’; and finally, the fourth theme identified focuses on the “Orientation of the workbook”.

Theme 1 – Content structure

The first theme, being content structure, translated between both groups of participants. When the participants were asked in the focus group about the general layout of the workbook, an agreement was noted between the HCP and patients with stroke participants in terms of their views on how good the workbook is laid out and set up.

“The layout of the workbook is good”; and, “The workbook is setup nicely. There’s a certain style and a good layout; this is where he has a stroke, and then there’s treatment to treat a stroke, and after he came home. You reflect and you can do better after that” – Patients with stroke.

“Various chapters had different layouts; but the layout of each specific chapter was uniform throughout, which was appropriate” – Healthcare Professional.

Theme 2 – Colour scheme

The second theme, that arose when the participants were asked about the general layout of the workbook, was identified as the two groups of HCPs were united in terms of their views on the use of the colour schemes in the workbook. The common threads around the colour usage was that the workbook needed to be simplified, warmer and more inviting to the user.

“The workbook is too busy, the colours need to be simplified for my eye”; and, “I found the colours to be a little bit depressing. The choice of colours for me is important; maybe something warmer, something more inviting, because this looks very cold and clinical” – Healthcare professionals.

Theme 3 – Sequencing of information

The second theme identified by the researcher in the category of ‘General Workbook Layout’, was identified as the participants raised similar opinions on the fact that certain chapters would be more appropriate if the sequencing of their information or placement of the chapters in the workbook were to change.

With regards to the ‘Layout’, the format of the chapters was identified to be simple, appropriate and highlighted relevant information; however, should be adapted to have the same format on both pages to prevent confusion when moving from one page to the next.

“(Managing my Stroke chapter) Very appropriate, simple and relevant questions asked. However, two different formats on each page causes confusion - It should be ‘My Question’ and ‘What we found helpful’, next page ‘My question’ and ‘What we found helpful’” – Healthcare Professional.

It was further highlighted by the participants that moving the ‘Reflection’ chapter, which is at the beginning of the workbook, to the end of the workbook would be more appropriate to allow for the user to first process how other patients with stroke reflected on their experiences before more effectively reflecting on their own experiences.

“Move (Reflection chapter) to the back of the workbook and give more space to document – to allow for clients to first read about others and then reflect more in-depth about their specific situation” - Healthcare professional.

Theme 4 – Workbook binding

Furthermore, under the general layout of the workbook, the fourth theme arose whereby the participants echoed each other in terms of their views on the practicality of the ring binding used for the workbook as it related to the use by patients with stroke. The common threads around the ring binding was that it was good and appropriate, especially for patients with stroke.

“The ring-binding is good”; and, *“The ring-binding of the workbook is appropriate for someone with a CVA as it is suitable for a left or right hemi; even if they have a hemi-neglect”* - Healthcare professionals.

Theme 5 – Orientation of the workbook

This fifth theme is one that translated across both groups of HCP and patients with stroke participants. Differing opinions were noted between the two HCP focus group participants, as well as between the two groups of patients with stroke, in their views of the appropriateness of the workbook orientation and size. A clear theme arose as both groups had strong opposing opinions on the matter. One group of HCP participants called for the workbook to remain in the current landscape A4 orientation, arguing that it is more suitable for the target population of patients with stroke.

“It is suitable and appropriate for a left or right-hemiplegic patient with stroke to manage the longer pages, as they are encouraged to do more activity to turn the page”; and, *“for the patients with stroke who have a hemi-neglect, it encourages them to look across the page and see all the content”*; and finally, *“the landscape orientation is more conducive to visual reception of all the information that is provided on the page; where portrait orientation may be too overwhelming for a stroke patient to take in the amount of information available”* - Healthcare professionals.

This argument coincided with the opinions of one group of patients with stroke, who highlighted the convenience and ease with which they were able to handle the workbook.

“(The workbook was) quite convenient to use”; “Easy to handle”; and also, “The workbook is manageable; you can read or browse, you can understand what's in it, the process, what to do, and what you should not do - So the musts and must-nots are in the workbook” – Patients with stroke.

Whereas, the other HCP group asking for the orientation to change to portrait A4 argued against these notions, highlighting that the current format would be difficult for a patient with stroke to manage effectively

“The workbook is too bulky with its current length”; and, “Patients with hemi-neglect would not see all the information presented on the page”; and finally, “Patients with stroke using the workbook in a wheelchair with tray tables would struggle as it is a too wide” - Healthcare professionals.

Further to this, the HCP participants made special mention of the good page quality and thickness; but that the workbook suffered from the fact that it had a soft cover.

“The workbook page quality and thickness was very good and appropriate as it makes it easier for the patient with stroke to flip the pages”; but that, “The workbook is a bit flimsy – I need both hands to hold it steady, which is not possible for stroke patients. My recommendation would be that a hard outer cover at the front and back page is required” - Healthcare professionals.

The other patients with stroke focus group concurred with this argument and highlighted that the A4 landscape size and soft covering was awkward and too cumbersome to manage easily; and made it impractical to transport around with them.

“The workbook should be a bit smaller, A5 size rather than A4. Then, perhaps you can put it into your pocket and carry it with you wherever you go”; and, “Should have a hard cover” – Patients with stroke.

3.3.2 Workbook Content

Within this category, five main themes arise that are highlighted amongst both groups of HCP and patients with stroke participants respectively. The first theme identified and presented focuses on the 'Variety of vignettes'; the second theme identifies the need for inclusion of a 'Young stroke'; the third theme involves the 'Content appropriateness' of the workbook; the fourth theme identifies the 'Picture appropriateness' of the images used in the workbook; and, the fifth and final theme presented in this category focuses on 'Stroke Education' in the workbook.

Theme 1 – Variety of vignettes

When the focus groups were asked about the workbook content, an agreement was noted between the two groups of HCPs and patients with stroke participants in terms of their views on the overall content and variety of the stories in that they were all inspirational. The HCP participants highlighted that there was a good mixture of various common problems or challenges experienced by patients with stroke of various ages; and each were specific to the affected patient, and what that patient found difficult.

"I liked that the stories that they told were specifically to that patient and what that patient found difficult"; "All the stories highlighted a variety of problems; it's quite a nice mixture"; "Variety of age groups in the stories is appropriate"; and that, "For a stroke patient, it's a nice little reference, all these different stories. Although I will definitely pick up from the one that I associate more with. So, you will have a lot of information, but actually you're only going to have the patient connect to a storyline. This is appropriate as you are making it available for a group and all different types" - Healthcare professionals.

The patients with stroke participants highlighted how good and appropriate the overall information presented in the workbook is; and how great their knowledge and understanding of their stroke and themselves grew from the information they read about the participants in the vignettes of the workbook was.

“The information in the workbook is quite nice”; and, “...to the point”; as well as, “The workbook was a great help; there was a lot of things that I learnt and can still learn from the workbook”; and, “When I read the workbook, I learnt more from it. After I realised what happened to me, this workbook showed me, it’s not the end of the world”; and finally, “By reading the workbook, I now understand that one can recover if you want to and that it becomes your own story” – Patients with stroke.

Theme 2 – Young stroke

The two HCP and patients with stroke focus groups were united with regards to their opinion on the need for inclusion of a young patient with stroke vignette in the workbook. The HCP stressed the need for the workbook to reflect the challenges of being a young patient with stroke; especially in the context of the SA population.

“I think the young stroke is applicable to our population, we’ve seen lots of young strokes”; and, “We have a lot of our younger population with stroke secondary to the high prevalence of HIV; it would be nice for them to also read this and say okay well someone else my age has also had a stroke, and they can maybe just relate to that person, instead of a 60-year-old” – Healthcare professionals.

While discussing which vignettes were identified as being the most appropriate, the patients with stroke participants identified Ben’s story, the young patient with stroke, as being particularly important.

“I believed that strokes only happen to people of a certain age; so, I was quite surprised to see that this guy is twenty-three years old. You can get a stroke at any age. A stroke doesn’t mean you have to be a certain age to have a stroke, it can come at any age” – Patient with stroke.

Theme 3 – Content appropriateness

From the overall discussions in the focus groups around the workbook content, opposing views were noted between the two HCP focus groups and the two patients with stroke focus groups. Although a consensus was reached within each particular group of participants. With the HCP participants, this theme received the most

attention during the discussions, with an agreement between the two groups with regards to the need to contextualize the workbook vignettes to be more appropriate for the South African context. It was also noted by the HCP participants that the first world culture was very evident in the story lines.

“The first world culture comes out in the stories through the talk of ‘holidaying’, the activities that they do, and the education level / occupations”; and, “It is obvious these stories are from a first world country; they have a lot of the facilities, like I see some of the stories where they quickly send someone a handrail to go up the stairs, and they use the buses and transport so easily. Not a lot of them are talking about I have to walk there, or I have to go fetch; so, I think the stories have to also be relevant to this country. Stories could perhaps reflect the more rural areas where SA population have to do so much more for themselves” - Healthcare professionals.

Furthermore, according to both focus groups of HCPs, the level of education and employment status of some of the participants included as vignettes in the workbook played a role in limiting the contextualization to the South African population.

“Some of the stories might not be that appropriate - A lot of the people in this workbook were educated and had a job. In the South African context, we have a high level of unemployment; and we have people that aren’t educated (literate)”; and, “If you are going to target the South African market, you need to be more focused on what you pick up on the patient’s circumstances; it’s very much, all these people that studied or so forth, your target grouping is very limited with this kind of storyline” - Healthcare professionals.

The overall opinion among the participants, of both focus groups of HCPs, of the need for contextualization for the workbook vignettes to the South African population was therefore clear; the vignettes need to be more representative of the various South African populations and ethnicity.

“Stories should be more representative of the South African population and ethnicity”
- Healthcare professional.

However, in opposition to the above points, during similar discussions held with the patients with stroke participants about the appropriateness of the vignettes included in the workbook; it was noted that the participants were in general agreement in terms of their views on how relevant and appropriate all the stories presented in the workbook are.

“I found that all of the stories were appropriate; out of them, I selected ones that appealed most to me. I could then apply it and try to do small things for myself”; and, *“All the stories were enjoyable and good, and help you in your own problem; but still it all depends on you, everything depends on how hard you are going to work”* – Patients with stroke.

Some examples highlighted in particular by the patients with stroke participants, were the stories of Fred, Jeanette and Comfort. Fred’s story was relevant to the participants because of the return of function he gained in his arm, and the fact that he was able to return to work.

“The exercises he showed for the arm were very good”; and, *“He had a stroke and then he decided that his is going to work on it to perhaps get him back to his part-time job. Now that appealed to me; I’m looking at him and I’m looking at myself, and maybe I can also get back to my job”* – Patients with stroke.

With Jeanette’s story, the participants could relate to her determination to overcome challenges in her path, in particular when her family pushed her to do things for herself.

“Her son encouraged her to get back to normal; I like this story because she did not give up”; and, *“When I asked my family to put on my pants and clothes, my wife didn’t; and I ended up doing it myself and I helped myself get done what I wanted to do”* – Patients with stroke.

The story of Comfort had a particularly strong influence on one participant, who highlighted the benefit she perceived in herself after reading the story and practicing similar exercises to what she saw in the workbook.

“I read her story last week and I practiced the same exercises as she did. You know, I couldn’t move this arm before, but now I can move my arm right up because I practiced” – Patient with stroke.

While discussing the workbook content, the patients with stroke did however, highlight several points they felt were lacking in the workbook. The first being that the stories focused on the patient with stroke once they were already in the community; and that there was nothing in the workbook about the care pathway or process from the acute hospital, to the intermediate facility, then to the community.

“There is nothing illustrating in the workbook about how they came in to hospital with the stroke, how they were handled by the therapists, the doctors, the nurses, to show that’s how he came in and there he goes out by the door, going back to his job. Also, a couple of pictures, where they do physio and stuff like that” – Patient with stroke.

Secondly, a disparity was recognised by a participant regarding the length of stay (LOS) in hospital and rehabilitation centres depicted by some of the people in the workbook verses the reality in the South African context, which left him feeling upset.

“What I want to change in the workbook is the time-period for recovery and rehabilitation after the stroke. They said to me at my hospital, you will stay six weeks at the stroke unit here; in that time, you must get healthy and strong. But the time goes too fast - Why is their time in hospital longer than our time? We are in the same situation as any stroke patient anywhere...It can’t be right” – Patient with stroke.

Thirdly, the perception that the workbook did not cover an issue that is prevalent in South Africa (SA), whereby people with disabilities are not accepted easily back into the community; and how to potentially overcome this barrier to reintegration.

“For us (SA patients with stroke), facing the people outside who won’t accept us (in our disabled state) is where the problem is. The workbook doesn’t show any help in dealing with that problem” – Patient with stroke.

Lastly, a point emphasized by a number of patients with stroke participants, surrounded the barrier of returning to work post stroke in South Africa; and the perception that the workbook did not depict this challenge.

“The workbook was telling me; these people just went back to their jobs, there were jobs for them. But, in South Africa, we don’t have that; the boss will say, I’m sorry you had a stroke, no deal, you have to go home”; and, “Our setup here is that when you get a stroke, your employer says that he is not able to employ you anymore. Our employers expect from us to be active and vibrant to do the work”; and, “It is not possible to go back to work, because your employer expects a more fit guy to work; instead of having guys coming off from a machine (previous role), to now work in the office or anywhere else in the factory”; and finally, “My employer came to visit me at hospital after my stroke and said, ‘You are a very good worker, but you must please understand, I can’t employ you any longer’; so there I was without a job” – Patients with stroke.

Theme 4 – Picture appropriateness

The participants were also of a united opinion with regards to the appropriateness of the pictures in the workbook, as identified in the fourth theme. The HCP participants identified the pictures to be very appropriate during both focus group discussions. The quality of the pictures was one focal point, that allowed for the user to relate to the reality of the situation the patient with stroke was in.

“I loved the pictures - the quality, it’s very real; and they’re nice, very simple, and people can relate to the reality” – Healthcare professional.

Both the HCPs and the patients with stroke highlighted the fact that the action pictures used in the workbook were of particular significance and most appropriate; with the HCP noting that the pictures helped the user relate to the story line.

“I think the pictures of the people who were actually doing different activities are really nice. It gives a flow of where the patient started at, and right up until the end basically.

It was easy to understand and to follow as well”; and, “The active photos helped to make the stories more relatable and appropriate” – Healthcare professionals.

The patients with stroke participants noted that the pictures visually represent the story before them and help to make what was read more relatable to them as the user.

“The pictures are important because, if I look at this guy’s facts and how he was, from the pictures I can then see the improvement in the situation” – Patient with stroke.

Certain pictures included in the workbook were however identified by the participants as being misleading; with the HCP group noting that certain pictures did not depict clearly the person’s disability, which impacted on the how well they were able to relate to the story.

“Some pictures of the people in the early descriptions of the workbook stories are close-ups, and don’t look like they have had a stroke – they look fully recovered; so as a reader, it is not easily relatable initially. But, the action pictures help to show the problems they are struggling with better and helped to make the stories more relatable and appropriate”; and, “Pictures helped to depict the participant’s actual disability. Not always able to see the challenges from just reading – Action photos very appropriate and important” – Healthcare professionals.

The patients with stroke participants noted that, in the workbook pictures where the people were happy or not showing signs or complications after their stroke, the participants found it difficult to relate fully to the story.

“The pictures don’t really show she (Comfort) had a stroke. She’s walking and she’s quite happy there...It’s not a negative thing, I can still relate to her story; but if I read the story, then I want to see she’s walking like me. I would be able to relate to the stories more if the pictures showed that they were similar to me” – Patient with stroke.

Other comments on the appropriateness of the pictures were that they highlighted the life of the patient at home and shows that one can integrate well back into society; and

that less literate patients with stroke, or those who have language barriers will also find benefit from the workbook as a result of the pictures.

“I really like that some of the pictures are the person in their life at home; so, it’s showing that you can integrate back into society”; and, “Pictures also help for the less literate patients who can visually relate to the situation; as they will relate to pictures before the content” – Healthcare professionals.

Finally, it was noted by the HCP participants that the pictures assist to improve the user’s level of self-efficacy through the use of vicarious experience, or observation of situations that the user would perceive as being similar to their own.

“The workbook has a very positive vibe to it. The visual input from the pictures help to give the reader direction with what they are reading, and allow one to think, if they could do it, so can I” – Healthcare professional.

Theme 5 – Stroke Education

During the focus group discussions between the HCP and patients with stroke participants, the need to include a ‘Why me?’ or ‘Stroke Education’ chapter in the workbook was made clear to the researcher as this opinion was noted consistently between both groups. The HCP participants noted that this addition would help the patients with stroke understand why they had a stroke and educate them how to prevent a further stroke from occurring.

“(In the workbook) There’s very little on what causes stroke, and the fact that once you’ve had one stroke, you have a much higher risk to have another stroke, and how do you prevent another. So whether it’s Hypertension, Diabetes or stress, there’s nothing in here that’s managing that aspect of it; and I think with our high incidents of lifestyle diseases, it would be really important to add that into self-management of a stroke”; and, “Also many of our patients know that they have high blood pressure, or high sugar and they know they must collect their tablets once a month, and they just know they must take their tablets, but the other sort of health promotion, no one really explains it to them until we ask them do you know why you had a stroke? So that aspect would be really, really important” – Healthcare professionals.

Further to this, in support of the theme, one HCP participant added a personal experience as it related to the importance of including stroke education.

“From personal experience, my dad had a stroke and he’s an educated person, and he asked me also: Why? What happened? Why did I have this? He kept asking in the beginning as well, he couldn’t understand why it happened to him and what was it? So, we had to keep explaining it to him as an educated person who has access to the internet, has access to private healthcare as well, to something where it’s written down and you can go back to it, or the person can go back to it, it’s there the whole time if you need an additional form in every group of education” – Healthcare professional.

Patients with stroke participants highlighted their misconceptions about stroke and the need for inclusion of a ‘Stroke Education’ chapter in the workbook. Participants had misconceptions as to how a stroke occurs, how it affects people, how to know when there is something wrong, and how to prevent having another stroke.

“At first, I thought a stroke only happens on your left-hand side, and now I see people are talking about the right-hand side. I didn’t know you can get a stroke on the other side. I want to know more about that”; and, “How much must the blood pressure (BP) be and when must you take your blood pressure to see if there’s something wrong with you”; and, “What I noticed about this workbook is that they gave a write-up of what happened to the people, but it doesn’t give a write-up of what to do to avoid getting a stroke or from having another stroke”; and, “All of us don’t get strokes the same way. If you read through the workbook, you see that all the strokes are different. But...what can a person do to prevent it going further or how can we help someone else who didn’t get a stroke yet?”; and finally, “Perhaps, the beginning of the workbook could have instructions of sort, to tell the people out there the dangers of stroke to begin with” – Patients with stroke.

3.3.3 Workbook User-Friendliness

Within this category, three main themes arise that are highlighted by the participants. The first theme identified and presented involves the use of ‘Language implementation’ in the workbook; the second theme involves the ‘Navigation tabs’ in

the workbook; and, the third and final theme in this category focuses on the 'Location of vignettes'.

Theme 1 – Language implementation

The theme of language implementation and ease with which the participants were able to read and understand the content is one that the researcher identified as translating across both groups, who were unified in their views on the appropriate implementation of language used throughout the workbook.

“(The workbook is) quite user friendly and I understood it; it was nice language that was used, easy to read and understand”; and, “Really like the overall content. (The participants in the workbook) spoke plain, simple language in a way that’s user friendly for a person who has had a stroke, and not a professional” – Healthcare professionals.

“The workbook is manageable, you can read or browse; you can understand what’s in it, the process, what to do and what you should not do” – Patient with Stroke.

Theme 2 – Navigation Tabs

Further to the above theme, agreement between the participants was also noted with regards to the workbook navigation tabs that highlight the various workbook chapters; with the HCPs expressing that they are appropriate to assist the user with navigating through the workbook; however, both groups indicated the tabs should be cut out for more effective navigation.

“The tabs are excellent, they give me structure in my thinking”; but, “(you should) cut-out tabs of the various sections of the workbook rather than it being flush...so you can see which section you’re in or want to go to” – Healthcare professionals.

Theme 3 – Location of vignettes

The final theme of this category on 'Workbook User-Friendliness' was one that translated across both HCP groups; with differing opinions seen between their views of the workbook location of vignettes. One focus group advocated for the location of the vignettes to remain as it is, with the stories playing out over several chapters of the

workbook. The opinion to leave it in the current format was highlighted based on the feeling that the flow of the various stories throughout the workbook was good. Not having one story finish, then the next starting, was appropriate; as it is about the user relating to, and remaining interested in, the patient's experiences throughout each.

“Flow of stories throughout the workbook was good – not one story finished then the next, which was appropriate. It is about the patient's experiences throughout the chapters” – Healthcare professional.

However, the other HCP focus group argued for the descriptions, stories, and pictures of each vignette to be kept all together as one. The argument to change the format of the vignettes to be kept together as one whole, where one is completed fully before moving onto the next, was based on their perception that it would provide better continuity for the user and prevent the need to flip back in the workbook; and that it would also help to make the pictures more relatable when you can visually see the challenges of the patient together with their storyline.

“Include summary of each story with cases to prevent having to flip back and forth”; and, “Keep summaries, stories and pictures (Keeping active) all together, rather than having the various sections all broken up for continuity – complete a story before moving onto the next. Helps make the photos more relatable when you can visually see the challenges they face” – Healthcare professionals.

3.3.4 Implementation of the SMI in the South African Context

Within this category, three main themes arise that are highlighted by the HCP and patients with stroke participants respectively. The first theme identified and presented is on the 'Benefits of the SMI'; the second theme involves 'HCP SMP training'; with the third and final theme identified in this category focusing on the potential 'Barriers to implementation' of an SMI workbook of this nature in the local context.

Theme 1 – Benefits of the SMI

When the participants were asked about the implementation of the SMI workbook in the local South African context, both focus groups of HCPs and patients with stroke

participants were unified in their views on the benefits of the SMI workbook of this nature; with a focus on the fact that it could go some way to motivating and assisting patients with stroke to reduce participation restrictions in an environment that is under-resourced with HCP and support service platforms.

“This workbook and intervention could be hugely beneficial, especially taking into consideration the lack of human resources in both private and government sectors of South Africa”; and, “It (the workbook) would work, even if it’s just from a motivational side”; and, “The reflection of keeping a diary and dates of what you did when is very self-motivating”; and finally, “Something like this (SMI) will be very good to implement - It will be really good, because sometimes they (patients) are unable to mobilise, and they don’t really see what’s going on, and sometimes they get a glance of a patient that’s in the exact same situation as them, and they see them doing something else, and sometimes it just gives them a motivation to try and push. I think that would be this workbook because you can read up and see there is that patient was in exactly the same situation I was in and it hasn’t limited them, so why should it limit me?” – Healthcare professionals.

The patients with stroke participants concluded by highlighted that they would have benefitted from having an SMI workbook of this nature during their rehabilitation process.

“Yes (this workbook would have benefitted us), we would have liked to have had something like this, from the start as it would have helped (in our rehabilitation)” – Patient with stroke.

Theme 2 – HCP SMP training

The second theme, which translated across the two HCP focus groups, was identified through their united views on the need for appropriate HCP training on the self-management programme (SMP) and SMI workbook prior to its implementation. Lack of knowledge in South Africa surrounding what self-management is, as well as consistency in HCP skill, and the HCP’s attitude, in delivering the SMP and SMI workbook as a tool was noted as being vital; where the HCP’s level of skill needs to

be sufficient to maintain the fidelity of the intervention, and the HCP's attitude needs to be positive about the workbook when introducing patients to it.

“South African healthcare professionals, and the patient population, are currently behind in terms of a mind-shift away from patient-HCP dependence” – Healthcare professional.

“The person (healthcare professional) that's going to introduce this to the patient, they need to all have the same level of training”; “The workbook needs to be implemented correctly, in the right format and with the right structures, and by trained HCP”; and, “They need to be positive about it (the SMP approach and SMI workbook) when introducing patients to it” – Healthcare professionals.

Theme 3 – Barriers to implementation

Discussions with the participants regarding potential limitations or barriers to the implementation of the SMI workbook in the local context surrounded three main barriers; namely: Cultural, literacy, and resource-constraint environmental barriers.

With respect to the cultural barrier, the HCP participants relied on their experience of dealing with patients with stroke when highlighting their view on this particular barrier.

“The SMI could possibly be more beneficial for woman than men due to South African population views on usual home ADL responsibilities and independence; with woman possibly having a higher need to return to an independent level of functioning than men due to their roles in the home” – Healthcare professional.

The concern of literacy as a barrier as it relates to the implementation of the SMI in the local context was highlighted by the HCP participants due to the fact that a large portion of the South African population is illiterate in reading or writing.

“Literacy is for me (a possible barrier)”; “I find this (workbook) to be very limited to a specific grouping of people, and you talking to those people. My heart goes out to the not so literate people that's not so able to read” “In South Africa, I want (this workbook)

to speak for the less literate, and more the type of patients that we've got here"; and, "From an educational...literacy level, a lot of like family members might also not be able to write" – Healthcare professionals.

Finally, in an already under-resourced, and time-constrained environment like that which is present in the South African healthcare system; the time factor for teaching HCP and patients with stroke to use an SMP, as well as manage the follow up appointments that are required to ensure sufficient support for the appropriate implementation for the SMI workbook, over and above what usual care / routine stroke rehabilitation is currently taking place, was raised as a potential barrier.

There are a lot of patients sent home straight (without any rehabilitation); and then they come to us maybe a few months later, and then it's a bit too late by then, unfortunately. So, I think if you should implement (the workbook), it should be implemented properly, and not just handed out in hospitals – 'read through this, this is going to help you'. It needs to be implemented correctly in the right format, in the right structures, with the proper trained professionals"; but, "having said that, in order to initiate using this tool, it wouldn't be as simple as just handing the book to somebody. For this first world (original Bridges stroke SMI workbook context), it mentioned 2 to 3 sessions to learn how to use the workbook. So, I don't even know if we have that sort of availability of 3 sessions, over and above the things that we want to be doing with the patient, so I think that would be a challenge" – Healthcare professionals.

3.5 DISCUSSION

3.5.1 General Workbook Layout

The first three themes identified by the researcher in this category, being 'Content structure', 'Colour scheme', and 'Sequence of information' translated across both groups of participants during the focus group discussions; and all relate to the design of the workbook. Both HCP and patients with stroke participants expressed similar opinions that the layout and structuring of the content within the workbook is appropriate as it is styled and uniform throughout; and therefore, set up in a way that allows for a good user-experience and active engagement with the content. All the

Bridges stroke SMI workbooks are professionally designed to ensure that the content structure, formatting, and layout follows best practices to afford the user the best experience. Reid (2017) reported that book layouts are specific and not a one-size-fits-all process; and that the design needs to be adjusted according to the particular style and genre required. Furthermore, “a strong book interior is pleasing and well-balanced in two important areas: typesetting (font, type size, space between the lines, and hyphens that break the lines) and layout (margins, columns, and illustrations and art); whereby, “thoughtful decisions at the outset of the book layout will ensure the process runs much more smoothly and the final product will be well-appointed and comfortable for the user’s eyes” Reid (2017). As the design of the Bridges workbooks are handled professionally, the researcher would not be able to implement design change, such as formatting and colour usage, until final sign off from the Bridges professional designer. The researcher reasons therefore that any required changes, as they relate to the workbook design, would be sent to the Bridges professional designer as recommended changes for the South African Bridges stroke SMI workbook.

However, with regards to the ‘Sequence of information’ of theme three, the participants identified that certain chapters would possibly be more appropriate if the placement of the chapters in the workbook were to change. They noted that moving the ‘Reflection’ chapter from the beginning of the workbook to the end of the workbook would potentially be more appropriate to allow for the user to first process and learn how other patients with stroke reflected on their experiences before more effectively reflecting on their own experiences through introspection. When reviewing the available literature on self-reflection and introspection, the researcher identified a literature piece focused on enhancing reflection in students, which draws similar parallels to patients with stroke learning about their new experiences post stroke. Costa et al. (2008, p. 221) noted the importance of reflecting and learning from experiences - “Most of us go through life viewing our experiences as isolated, unrelated events; viewing these happenings simply as the experiences they are, not as opportunities for learning. Instead, we want students to get into the habit of linking and constructing meaning from their experiences; such work requires reflection”. Costa et al. (2008, p.221-222) further notes that reflection “involves linking a current experience to previous learnings (a process called scaffolding)”; and that, “Reflection

also involves drawing forth cognitive and emotional information from several sources: visual, auditory, kinaesthetic, and tactile”. Therefore, to effectively reflect, “One must act upon and process this cognitive and emotional information, synthesizing and evaluating the data. In the end, practical self-reflection means applying learnings to contexts beyond the original situations in which the learning occurred”. However, according to Costa et al. (2008), one way to derive rich meaning from one’s experiences is through ‘Modeling Reflection’, whereby individuals learn from role models, or people viewed as being in similar situations who are actively reflecting on their experiences. Furthermore, students hearing an external voice of reflection in others’ comments, suggestions, assessments, evaluations, and feedback is important, because this kind of reflection multiplies the learning for each individual. Therefore, the researcher reasons that moving the ‘Reflection’ chapter of the Bridges stroke SMI workbook from the front of the workbook to the back could afford the user the opportunity to learn from the experiences and reflections of others; and therefore, improve the self-reflection and introspection process.

Theme four, being ‘Workbook binding’, arose whereby the participants echoed each other in terms of their views on the practicality of the ring binding used for the workbook as it related to the use by patients with stroke. The common threads around the ring binding was that it was good and appropriate, especially for patients with stroke. Beaty (2018) maintained that there are several benefits that ring or ‘spiral’ binding offers to users. Firstly, the pages can open 360 degrees, allowing for easier referencing and saving space, which is ideal for instructional books. Secondly, the pages turn easily and stay put due to the lack of spinal tension on the pages. Thirdly, the binding can accommodate low or high page count. Fourthly, spiral binding works ideally well with books that have index tabs, as the pages turn freely and do not need to be manually held open, which allows for quick location of a specific section or chapter. Lastly, it is a readily available binding method (Beaty, 2018). All aforementioned benefits tie in well with the requirements for implementation of this stroke SMI workbook in the local South African context; and therefore, no change would be required by the researcher.

The fifth theme, being the ‘Orientation of the workbook’, whereby HCP and patients with stroke participants held differing opinions on the orientation, size and convenience of the workbook, warrants further discussion as both groups highlighted this point with

contrasting views. Two focus groups, one being HCP participants and the other being patients with stroke participants, concurred in their views and reasoned for the workbook to remain as it currently is in landscape A4. This reasoning was based on the HCP views that the longer pages were more suitable and appropriate for patients with stroke as the current orientation encourages the individuals to do more activity and look across from left to right at all the available content; also allowing for more effective visual reception of the presented information for those with visual-perceptual difficulties, as the information in their field of vision is not too overwhelming, as would be the case if the information were to be presented in portrait orientation. This was coupled with the views of the patients with stroke that the workbook, in its current landscape orientation, was convenient, easy to handle, and manageable.

Whereas, the other HCP and patients with stroke groups argued for the orientation and practicality to change from being a landscape A4 soft cover workbook to portrait with harder outer covers instead. This was based on the HCP views that the current format would be too difficult for a patient with stroke to manage the workbook effectively, as it is too bulky and flimsy, especially for those using the workbook in a wheelchair; and that patients with hemi-neglect would not be able to see all the information presented on the page as some information would be outside of the available field of vision. This was coupled with the views of the patients with stroke that the A4 landscape size and soft covering was awkward and too cumbersome to manage easily; and made it impractical to transport around with them.

The groups who reasoned for the workbook to remain in its current format did so from the perspective of using the workbook, and not just its contents, as an activity or exercise to assist in the rehabilitation of the patient with stroke; whereas, the groups who argued for a change in the workbook format reasoned from the perspective that the workbook should accommodate the challenges of the patients with stroke so that the content can be more effectively delivered to the user.

Both views are plausible, understandable and acceptable. Based on available literature, Jutai et al. (2003) explained that visual perceptual disorders are a common clinical consequence of a stroke, occurring in as many as 30% of patients with stroke; and occur when there has been an injury to the cortical or midbrain areas. A few examples of the major forms of visual perceptual deficits include: 'Agnosia', which

refers to the inability to recognize an object by sight despite adequate cognition and visual acuity/field; 'Alexia', which refers to the inability to recognise or comprehend written or printed words; and, 'Unilateral spatial neglect', which refers to an inability to attend to or respond to meaningful sensory stimuli presented in the affected hemisphere. Visual perceptual deficits, such as unilateral neglect, have a negative impact on the functional recovery and long-term outcomes of a patient with stroke. Cicerone et al. (2000) suggested that rehabilitation for visual perceptual deficits should include the use of a technique known as 'visual scanning', which improved compensation for visual neglect, and was found to be superior to conventional physical therapy inputs). Based on a systematic review, conducted by Jutai et al. (2003), nine studies with various levels of methodological quality, found strong evidence that rehabilitation using primarily enhanced visual scanning techniques improves visual neglect and functional outcomes post stroke.

Therefore, the researcher reasons that the argument for the workbook to remain in landscape format is appropriate, whereby the orientation can function in conjunction with the content to further benefit the user; as long as visual scanning techniques are being employed by the user. Therefore, it becomes imperative that, as part of the HCP training on the SMP programme and delivery of the SMI workbook, that visual perceptual difficulties are highlighted and addressed, so that the HCP can engage appropriately with the patient with stroke who may have this clinical disorder to ensure that visual scanning behaviours are implemented during use of the workbook.

The researcher also noted the feedback from the participants on the practicality that hard covers would provide for a workbook of this nature, in terms of providing stability for patients with stroke while they are handling the pages and reviewing the content. Due to the physical the cognitive impairments post stroke, such as hemiparesis, communication and visual-perceptual difficulties, as highlighted by WHO (2006) in Chapter 1.1.2.1, patients with stroke would benefit having this stability at the front and back of the workbook to reduce difficulty in opening, and maintaining their place within, the workbook. As this change ultimately impacts the final version of the South African Bridges stroke SMI workbook to be distributed to the patients with stroke; the researcher would therefore propose this change to the professional designer for implementation.

3.5.2 Workbook Content

Themes one and two highlight clear consensus between all focus groups on the appropriateness of the overall workbook content, as it relates to the variety of stories and the importance of including a vignette that depicts a young patient with stroke, in achieving the outcomes of building the user's self-efficacy in the South African context; especially due to the high prevalence of the young strokes secondary to Human Immunodeficiency Virus (HIV) in South Africa.

Griffiths et al. (2011) identifies, according to consensus amongst available literature, that a 'young stroke' pertains to individuals under 45 years of age; and that as the incidence of stroke is directly proportional to age, stroke in younger people is less common. However, stroke in a younger person can be even more devastating in terms of productive years lost and the overall impact on the young person's life. Overall incidence rates under the age of 45 range from 7 to 15 in 100 000 people/year for all stroke; however, there may be a greater incidence of stroke in low-to-middle income countries related to socioeconomic variables, although high rates are observed in the South African black population of all ages (Griffiths et al., 2011). Bryer et al. (2010) clarifies that, although the incidence of stroke increases with age, as in all population groups, in the black South African population some studies have found that the incidence of stroke in the younger age groups (35 - 54 years) is higher than that found in other populations. Furthermore, Bryer et al. (2010) observed that stroke management, particularly in the young South African population, is complicated by the high prevalence of HIV. According to the annual report presented by Statistics South Africa for 2015/2016, 29.2% of South Africans had an infectious disease, including HIV (Statistics South Africa, 2016). The HIV infection may cause a stroke through opportunistic infections, secondary to involvement of the heart, possibly by changes in coagulation factors, and through direct or indirect damage to blood vessels (Bryer et al., 2010). Hoffman (2000) found that, in South Africa, race and endemic disease both appear to be important determinants of stroke in young adults. As the workbook was found to have variety in the included vignettes, as well as a young stroke story already included; no additional change was required by the researcher in this regard.

Theme three however, focuses on the actual content of each vignette in the workbook, which highlighted opposing views between the HCP and the patients with stroke

participants. The HCP participants argued that the stories included in the workbook reflected a first world country and did not reflect the South African culture enough to be applicable to this setting; however, the patients with stroke participants had the opinion that the stories were appropriate and relatable to them. The HCP focused more on the abstract information around the included vignette content, such as the socio-demographics and cultural relevance of the information provided; whereas the patients with stroke focused more on the storyline and the available concrete, surface information.

This occurrence could be attributable to several factors. The first, and most simple being that the HCP participants were actively seeking areas for improvement in the workbook; while the patients with stroke had less of an interest in what the deeper meaning of the content entailed and were satisfied and content to apply meaning to the surface information available to them. The second, more in-depth reason, could be that, for the patients with stroke, areas of the brain that are responsible for thinking and reasoning, could be somewhat impaired. Moawad, (2017) reported that the brain works in a sophisticated way to develop thoughts, incorporating a number of areas within the brain so as to integrate information; and that, thinking skills refer to a range of processes, such as consciously remembering information, solving concrete or abstract problems, and incorporating reasoning, insight or ingenuity. Ylvisaker et al. (2006) noted that abstract thinking is a level of thinking about things that is apart from the immediate information or facts of the 'here and now' and removed from specific examples of the concepts being thought about. However, due to the cognitive impairments post stroke, the patients with stroke may not have been able to add this level of thinking to their feedback on the workbook. Nys et al. (2005) observed that, the intricacy of the executive functions and underlying network in the brain make them highly vulnerable to injury. Furthermore, "cognitive disorders (such as impaired thought processing post stroke) are related to the lesion itself; but often also to hypoperfusion and functional deactivation (diaschisis) of more distant areas in the brain"; whereby, "both ischaemic and haemorrhagic stroke may cause symptoms by exerting pressure on the surrounding brain tissue and by causing a deviation of nearby or more distant brain structures" (Nys et al., 2005, p.25).

The patients with stroke did however raise several concerns of their own about the included content, relating to the available healthcare resources and vocational opportunities that were reflected in the workbook vignettes. With the first concern, it was highlighted by the participants that the patients in the UK appear to be afforded a longer length of stay (LOS) in a rehabilitation unit than that of similar patients in South Africa. As part of the mandate of Intermediate Care for patients in South Africa, a maximum of 42 days (around 6 weeks) LOS is afforded to all patient population groups, regardless of medical condition and level of function, before being discharged into the community to continue as an out-patient using community resources (WCDOH, 2007). As recovery post stroke can be seen, albeit at a slower rate, years after the initial insult, as described by Hellstrom (2002) and Staines et al. (2009) in Chapter 1, section 1.1.4; the mandate of 42 days for stroke rehabilitation does limit the potential for optimal functional recovery; and therefore, places a greater burden on the patient, the family, and the community resources to minimize the morbidity level post discharge from Intermediate Care. An argument could therefore be made to the Department of Health to increase this mandated LOS, for the stroke patient population group in particular, to maximize recovery prior to community discharge.

The second concern raised by the patients with stroke surrounded the perception that the jobs in the UK were readily available and waiting for the individuals post stroke. Unemployment in South Africa is one of the major challenges affecting the majority of persons with disabilities and their families. The Census 2011 report on the 'Profile of Persons with Disability in South Africa', conducted by Statistics South Africa (2014), highlighted that 5.3% of the population of Western Cape were persons with disabilities. Within this report, under 'Employment policy framework for persons with disabilities', Statistics South Africa (2014, p. 9-10), reported that, "many countries, including South Africa, have adopted laws and policies that promote the employment of persons with disabilities in regular jobs, including quotas or targets, anti-discrimination measures, positive employment measures, job retention or return-to-work measures and alternative employment policies...including those individuals who acquire a disability during the course of employment, by taking appropriate steps to ensure that they are not discriminated against". However, the report notes that this framework is not easily monitored and enforced in South Africa. The Department of Labour is mandated to monitor commitment to an inclusive employment practice stipulated in a number of

legislations and policies, namely: The Employment Equity Act (1999), Black Economic Empowerment Act (2003), Labour Relations Act 66 of 1995, and Public Service Act of 1996; which, among other things, aim for the attainment of 2% target for persons with disabilities in the public service. Some indicators measuring access to employment however show little progress in this regard; with the Employment Equity Report of 2011 showing that persons with disabilities only constituted 1,4% in total (Statistics South Africa, 2014).

The exclusion of persons with disabilities from work imposes a financial burden on the individual and their families; and often translates into impoverishment, particularly for those in under-resourced communities. Persons with disabilities are often excluded from employment due to a number of factors, such as: discriminatory attitudes and practices from employers, past ineffective labour legislations, inaccessible and unsupportive work environments, inadequate access to information, inaccessible public transport, a lack of enabling mechanisms to promote employment opportunities; inadequate and inaccessible provision for vocational rehabilitation and training; a lack of access to financial resources; and, a lack of skills due to inadequate education. Negative societal perceptions concerning persons with disabilities are prevalent; whereby societies think that a person with a disability is unable to work, because the person is viewed as sick. In addition, employers lack confidence in the abilities of a person with disabilities even though the person is qualified. These perceptions lead to persons with disabilities losing confidence in themselves (Statistics South Africa, 2014).

As a result, only a few persons with disabilities get jobs in the open labour market, leaving the majority working in sheltered/protective workshops run by the Departments of Social Development and Labour, by private welfare organisations or by persons with disabilities themselves. Low levels of employment of persons with disabilities have socio-economic implications, such as poverty and dependency on the social security system in the form of disability grants, among others. Unemployment rates of persons with disabilities are extremely high, particularly in low-to-middle income countries. Eight in ten persons with a disability are unemployed, making discrimination in terms of denial of employment opportunities one of the worst challenges faced by people living with disabilities (Statistics South Africa, 2014).

Based on the above findings and the identified literature, the researcher reasons that several of the UK vignettes are appropriate for inclusion in the draft South African Bridges stroke SMI workbook; however, the socio-economic status of the general South African disabled population is not currently reflected, and needs to be ratified during the process of adaptation and contextualization of the workbook through the addition of local South African experiences of living with stroke for applicability to the South African stroke population so as to minimize the negative perceptions and ultimate impact on the South African user.

Theme four found further consensus between the two groups of participants in their views on the appropriateness of the pictures included in the workbook; with both groups indicating the importance and relevance they had to ensuring the user was able to relate to the story content to achieve the desired effect on improving the individual's self-efficacy. Both groups however stressed the importance of the pictures accurately reflecting the disability as it relates to the story unfolding in the workbook, so as to ensure the user views the participants included as vignettes as being similar to them. The pictures therefore need to support the content that is being delivered to the user to add to the overall impact. For the less literate patients with stroke, or patients with stroke who have communication disorders, the included pictures were also emphasized as being integral to the overall experience of the workbook as the users would be able to relate to these contextual pictures to understand the content more comprehensively. Dietz et al. (2006, p.1) reports that contextually-rich images are "pictures, photographs, or images that represent situations, places or experiences by depicting people or objects in relation to one another, the natural environment, and the central action of a scene"; and, "provide a way to represent meaning and serve as a platform for co-constructing messages". In this way, if the visual images provided in the workbook are contextually-rich, the users would be able to communicate and interact with the workbook more effectively and gain more benefit. Dietz et al. (2006, p.1) observed four criteria for evaluating images for contextual richness, namely: "Environmental context – setting, people, objects, activities; interactions with people or the environment; personal relevancy; and clarity regarding elements key to the implied relationship". The researcher reasons that the addition of contextually rich, South African pictures in the South African Bridges stroke SMI workbook, that depicts

the patients with stroke in action so as to support the content being delivered, is necessary for the benefit of the user.

Theme five in this category again found consensus between both groups of participants in their views of the need to include a 'Stroke education' chapter in the workbook to help the user understand why they have been impacted by a stroke, and to educate them on how to prevent further strokes in the future. The initial concept of helping the user understand why they have been affected by stroke is important to mitigate the negative effects grief may have on the functional recovery and participation of the patient with stroke. A natural progression of the grief process after an acute and traumatic event, such as a stroke, as identified by the personal account from the HCP when discussing the need for inclusion of Stroke Education, is to question 'Why me?'. According to the Stroke Foundation (2017) grief is a symptom that is associated with all forms of loss, such as the loss experienced by a patient with stroke in terms of quality of life and independence. Survivors of a stroke are likely to move through seven stages of grief, not necessarily in an orderly fashion, namely: 1) 'Shock and Denial', whereby patients with stroke, and possibly their family members, react to the stroke with disbelief or total denial; and may last several weeks. 2) 'Pain and Guilt', whereby patients with stroke are likely to experience physical and emotional pain; as well as guilt or remorse over things that done or not done before the stroke. 3) 'Anger and Bargaining', whereby frustration gives way to anger, and blaming is common; during this stage, patients with stroke often ask: 'Why me'? 4) 'Sadness, Reflection and Loneliness'; whereby patients with stroke may experience a long period of sad reflection when the magnitude of one's loss is realized. Normal feelings of despair are noted; and encouragement from others often does not help. 5) 'The Upward Turn'; whereby adjustment to life after a stroke starts and the patients with stroke physical and emotional symptoms are more controlled. 6) 'Reconstruction and Working Through'; whereby patients with stroke seek realistic solutions to problems encountered; and start to plan for their future. 7) Finally, 'Acceptance and Hope'; whereby patients with stroke learn to cope with the reality of the situation (Stroke Foundation, 2017).

The second concept of educating patients with stroke on how to prevent further strokes in the future is not only important to promote good health literacy and prevent recurrent

stroke for the individual affected but also with respect to encouraging health promotion both for the individual and the community they are involved with. According to Fu et al. (2015), the rate of recurrent ischaemic stroke (IS) has been reported to be approximately 12% during the first year after the initial stroke; however, the World Health Organization MONICA project reported that the rate of recurrent stroke was closer to 27% (Thorvaldsen et al., 1995). As a result of the high incident rate of recurrent strokes or transient ischaemic attacks (TIA), there is an imperative need for improved health consciousness of all patients with stroke. Wangqin et al. (2017), noted that stroke is associated with a 10% to 20% increased risk of subsequent stroke in the first 90 days following the stroke event. Burn et al. (1994) reported that, although the absolute and relative risks of recurrent stroke are highest early after the first stroke; this risk remains elevated for several years thereafter. Efforts at secondary prevention should be initiated as soon as possible and continued for several years to gain greatest benefit. Patients, who suffered a stroke at a young age, are at higher risk of recurrent vascular events and even death. Vascular risk factors are common in younger adults; and secondary prevention measures, targeting these vascular risk factors, may diminish the risk of recurrent vascular events. Regular screening of risk factors after stroke, particularly in those with increasing age, having other vascular risk factors, or a family history of diabetes, yields potential for secondary stroke prevention (Rutten-Jacobs et al., 2014).

Therefore, the researcher reasons that having a chapter in the workbook aimed at Stroke Education, acknowledging this grief process and health promotion strategies, may assist the users in not only dealing with their emotions and moving through the stages of grief more effectively; but also manage their health more effectively so as to prevent further primary and secondary complications resulting from stroke.

3.5.3 Workbook User-Friendliness

Theme one involves the appropriateness of the language implemented in the workbook, which was noted by the participants as being simple, user-friendly, and easy to understand for patients with stroke. As this workbook is specifically aimed at being relevant to the general patient population, who may have low health literacy and have not been educated regarding medical terminologies; it is important to use plain, simple, and understandable language to encourage a positive impact on the user's

self-efficacy, which requires that the user relates to the content and individual as being someone in a similar context to themselves. The importance of the user viewing the information in the workbook as being provided by individuals they see as being in a similar position to them, and not coming from 'external' outside sources such as healthcare professionals who have not experience the deficits that the patients have, is prevalent in this theme. An improvement in self-efficacy would therefore not be achieved as effectively if the language used was from the mouths and minds of medical personnel.

The use of common and simple language that is relevant to patients is not a new approach in healthcare. The Centre for Disease Control and Prevention (CDC, 2016) reported that simple language makes it easier for individuals to understand and make use of health information; but that, many organizations don't implement plain language as often as they should. Du et al. (2016) concurred and added that the idea that patients should receive understandable healthcare information for the purposes of more effective decision-making is not revolutionary; however, the quality of information being provided to patients is generating increasing concern. When providing high-quality health information, Du et al. (2016) stressed that healthcare professionals must use simple and understandable language; especially for patients with communication disorders or low health literacy.

The widely accepted definition of health literacy, as described by Selden et al. (2000), is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Nielsen-Bohlman et al. (2004) noted that the Institute of Medicine (IOM) report on health literacy found that there was a major mismatch between the health information patients received and what they understood; and, that the lack of understanding was not primarily the fault of the individuals receiving the information, nor was it solely or primarily the result of poor or limited literacy skills. According to the IOM, highly skilled people, especially when made more vulnerable due to poor health also find the healthcare systems too complicated to understand. The IOM and other organizations propose using plain language to address the needs of those with limited literacy skills, as well as those with limited health literacy skills. The idea is that plain language helps people understand health information because the writing style is clear, concise,

organized, and jargon-free. Documents written in plain language are less complex and therefore easier for everyone to understand, including people who have limited literacy skills, limited health literacy skills, or both (Nielsen-Bohlman et al., 2004). Du et al. (2016) concludes by indicating that healthcare professionals, in collaboration with stroke survivors, need to develop information materials that are useful and understandable. If patients with stroke are involved, the information will be much more likely to be relevant, acceptable, and understandable to stroke patients. Based on the above finding, and the available literature, the researcher reasons that there is no need for any adaptation in the use of language delivery in the workbook.

Theme two discusses the use of the navigation tabs in the workbook; with the participants highlighting the appropriateness of the tabs, but that the workbook and patients with stroke would benefit from the tabs being cut-out for easier navigation of the various chapters. This was based on the opinion that it would allow for ease of reference and movement when attempting to move between chapters; but also, as a result of the clinical presentation of impaired fine motor skills in patients with stroke, cut-out tabs would serve multiple purposes, such as: a compensation strategy, making handling of the workbook pages, and moving between chapters, simpler; and as a task that the patient with stroke can perform to improve fine motor fallouts. Ward (2014) observed that, after a stroke, rehabilitation interventions may involve, amongst others, compensation strategies and task-specific training aimed at reducing impairments and improving a patient's functional abilities. As this is a design component of the workbook, the researcher proposes to include this as a recommendation to the professional designer for the South African Bridges stroke SMI workbook.

Theme three focuses on the orientation of the vignettes and the continuation of the stories throughout the various chapters of the workbook; with differing opinions within the two HCP participants groups. One group advocates for the current flow of vignettes and content layout throughout the workbook to remain so as to keep the user engaged with the storyline as they move through the chapters; and one group arguing that the stories should be kept together from start to finish, before moving on to the next story, for continuity and ease of reading. The patients with stroke did not discuss this as a point of interest. Therefore, based on the overall positive feedback regarding the

content layout, the researcher reasons there is no obvious benefit to adapt the vignette orientation; and therefore, will remain with the current format.

3.5.4 Implementation of the SMI in the South African Context

Theme one notes the benefits of the workbook, as highlighted by both groups of participants, taking the South African context into consideration. Two benefits were highlighted during the focus group discussions. Firstly, the SMP and SMI workbook could assist in reducing the current dependency that patients have for healthcare provision by healthcare professionals and shift the focus onto the individual managing their own healthcare if they have been empowered to do so through the SMP and SMI education and usage; thereby relieving the pressure on the healthcare system in South Africa and encouraging patients to use available community healthcare resources more effectively and efficiently. Secondly, through the general motivational aspect of encouraging patients with stroke to attempt to be more independent and participate more actively in tasks, and to be more active members of the community; thereby reducing participation restrictions and the subsequent burden of care on the community.

Rowe et al. (2006) reports that there is a natural trust relationship between healthcare professional and patient as a result of the vulnerability associated with being ill, the information asymmetries arising from the specialist nature of medical knowledge, and the uncertainty and element of risk regarding the competence and intentions of the practitioner on whom the patient is dependent. Furthermore, patients have traditionally placed high levels of trust and dependence on healthcare professionals for the management of their health. Jones et al. (2016, p.472) noted that “rehabilitation delivered in an acute stroke care setting can unwittingly preference the competencies and techniques of therapists over and above the contributions and skills of patients and families”. Grady et al. (2014) however identified that approaches to managing chronic illness, such as the implementation of an SMP, have shifted the focus from the traditional healthcare provider-patient relationship to a paradigm in which individuals with chronic conditions play a key role in guiding their care, in partnership with, and supported by, healthcare providers. Coulter et al. (2008) emphasized that, at some point, all people have to make important health decisions that affect their health outcomes. Patients can therefore play an important role in understanding the causes

of illness, protecting their health, and taking appropriate action, choosing appropriate treatments for acute episodes of ill health, and managing chronic illness. Strategies for promoting an active role for patients should pay attention to health literacy, shared decision-making and self-management; with a number of interventions shown to be effective in building health literacy, promoting patient involvement in treatment decisions, and educating patients to play an active role in self-management of chronic conditions, including education self-management programmes (SMP).

All SMPs are directed at enhancing the ability of individuals to improve their health status, regardless of where the individual may fall on the health-disease spectrum. Five core processes that are positively impacted, as a result of the development of self-management in an individual, include: problem solving and decision-making abilities, more efficient resource utilization, improved partnership with healthcare professionals, and improved willingness to take action (Grady et al., 2014).

Coulter et al. (2008) cautioned though that differences in morbidity patterns, cultural barriers and social inequalities must be taken into account when planning strategies to promote greater patient engagement of self-management. However, if these aforementioned barriers can be overcome, the rewards are potentially great, as individuals who are more informed and engaged tend to use fewer healthcare resources and to make more appropriate choices, leading to better health outcomes. In addition to the potential for achieving greater efficiencies in resource use, encouraging patients to take more control when they are ill may also prove to be an effective tool for improving public health and therefore a lower the community burden of care.

Theme two discusses the need for appropriate HCP training on the self-management programme (SMP) to ensure the fidelity of the SMP and SMI remained throughout implementation. Consistency in skill, and the HCP's attitude, in delivering the SMP and SMI workbook as a tool was noted as being vital; where the HCP level of skill needs to be sufficient to maintain the fidelity of the SMP, and the HCP needs to be positive about the workbook when introducing patients to it. Hardeman et al. (2009) explains that quality assurance in interventions is often referred to as 'treatment fidelity'; which includes methodological strategies to monitor and enhance reliability and validity of interventions. Training of healthcare professionals, one of five

components to ensuring treatment fidelity, is necessary as the competence of the practitioner directly influences to what extent contextual and interpersonal variables affect delivery of the intervention. Practitioners need to be adequately trained to deliver the intervention as intended, and to maintain standardization of delivery over time (Hardeman et al., 2009). The researcher notes the imperative nature of supportive HCP training for the successful implementation of the Bridges SMP and stroke SMI workbook; and will advocate for the inclusion of such training with any implementation of the tool in future.

Theme three notes the potential barriers to the implementation of a SMP and SMI of this nature; with the HCP participants highlighting that different cultural values, lower literacy rates, and a healthcare resource constrained environment that may play a role in negatively impacting on the outcome of the SMI implementation in the South African context. According to Ch'Ng et al. (2008), understanding the barriers faced by those who have suffered a stroke is useful to identify the longer-term issues that primary care-based services for stroke will need to address.

The cultural barrier was highlighted by the HCP participants who were of the opinion the SMI workbook may be more effectively implemented with women in South Africa due to the historical perspective that women need to be able to be functionally independent to care for the family and the home; while men are at work and earn an income. However, this view places a higher value on managing the family and home life, than on providing an income for the household. It could however be argued that the psychology behind returning to functional independence for the purposes of providing for one's family, and that of returning to paid employment would be similar, albeit for different reasons regardless of gender role.

When reviewing the literature, Idang (2015, p.98) observed that culture, among other aspects, "embraces a wide range of human phenomena, norms, and beliefs"; and that, "it is the patterned way of life shared by a particular group of people that claim to share a single origin or descent". Furthermore, "culture, as it is usually understood, entails a totality of traits and characters that are peculiar to a people to the extent that it marks them out from other peoples or societies. These traits go on to include a people's social norms, taboos and values; with values here understood as beliefs that are held about what is right and wrong and what is important in life. It is true that culture is

universal and that each local or regional manifestation of it is unique” (Idang, 2015, p.98).

A study conducted by Wegner et al. (2015, p.1), on cultural beliefs in rural South Africa, cited concurring literature, stating that “cultural beliefs define who people are, how they interact with the world and how they behave in certain situations; and can be considered a combination of religious beliefs, socially accepted norms and traditions (Bailey et al., 2000; Omu et al., 2012; and Maart et al., 2007)”. Furthermore, “culture plays a central role in health-related behaviours (Carroll et al., 2007; Omu et al., 2012)”; whereby, “different cultural groups have vastly different perceptions of the causes of disability and disease, and these perceptions influence their health seeking behaviour (Bailey et al., 2000; Legg et al., 2013; Pronyk et al., 2001)” Wegner et al. (2015, p.1).

Ultimately, as culture is so ingrained in our psyche and way of life; the role that cultural beliefs have as a barrier on the effectiveness of the SMI implementation should be less of a focus for HCP than the way in which the tool is delivered. The researcher reasons that the barrier of culture could therefore be mitigated through the HCPs being more in-tune, and culturally aware of how best to approach and deliver the SMI workbook to patients with stroke who may have certain cultural beliefs or values. With this in mind, Wegner et al. (2015, p.2) cited further evidence that stated, “healthcare professionals’ lack of cultural awareness may lead to cultural imposition (Campinha-Bacote 2002)”; whereby, “in order to provide an effective and culturally responsive healthcare service to the multi-cultural population of South Africa, healthcare workers need to be culturally aware and competent (Carroll et al., 2007; Campinha-Bacote 2002)”. In conclusion, Wegner et al. (2015, p.2) stated that, “cultural beliefs can be considered as personal factors within the International Classification of Functioning, Disability and Health (ICF) framework that could potentially disable a person with an impairment”; and cited (WHO 2001) which emphasizes the importance of the healthcare professionals identifying personal and contextual barriers associated with cultural beliefs would assist in minimizing activity limitations and promote the integration of individuals with disability into society (Wegner et al., 2015, p2).

The perceived barrier of lower literacy rates in South Africa is pertinent in this context; as patients with stroke need to be able to engage actively with the content of the SMI

workbook. When reviewing the available literature, the researcher identified evidence that South Africa is progressing steadily with respects to the level of population literacy for people above 15 years of age. According to The World Bank (2018), the latest literacy figures for South Africa in 2015 place the level of literacy at 94% of the population who could read and write. Although this still represents a number of people (6%) who are illiterate in reading and writing, the majority of the population would not have difficulty with this perceived barrier. The researcher however reasons that the workbook could still have a benefit for the 6%. In a clinical context, literacy can be likened to a communication disorder; and in that respect, patients with stroke who have communication disorders can still find benefit from the workbook through assistance from carers, family members or the HCPs to deliver the content.

Finally, in an already under-resourced, and time-constrained environment like that which is present in the South African healthcare system; the time factor for teaching HCP and patients to use an SMP, as well as manage the follow up appointments that are required, over and above what usual care / routine stroke rehabilitation is currently taking place was raised as a concern by the participants. Jones et al. (2016) confirmed that it is a common perception that self-management support can take more time than usual practice; and that an SMP delivered in addition to routine stroke rehabilitation has cost and time implications, especially when utilizing an individualized approach. However, if the SMP could be integrated into existing rehabilitation, it may be both clinically valuable and cost-effective. Jones et al. (2016) therefore conducted a study with the aim to test the feasibility of a cluster-randomized controlled trial into the effectiveness of the Bridges stroke SMP when integrated into community rehabilitation or 'usual care' model. As an example, one community stroke team achieved comparable outcomes to the other intervention site, but with 50% less resources. Investing the time to listen to stroke survivors, to discover what is important and meaningful to them, could in actual fact save time in the long term. Based on the design and using a nested process to evaluation, the Bridges SMP integration was found to be feasible; and the intervention was delivered according to predetermined markers of fidelity (Jones et al., 2016).

The researcher therefore reasons that this barrier requires a mind-shift change, not only from the patients, but more importantly from HCPs who would need to see the

ultimate goal / bigger picture of implementation; and that, if done correctly and consistently by all HCP, could play an important role in alleviating healthcare services and resources rather than taking up more. It would however, require concerted effort and commitment to the ideology and concept of self-management for it to have lasting benefits for the South African population. Jones et al. (2012) concurred that it may be more efficient to integrate self-management programmes into stroke rehabilitation and usual care; but that adoption of these methods by healthcare professionals who are used to a specific acute model of care is likely to require some fundamental changes in working practices.

3.6 SUMMARY

From the four categories used to discuss the Bridges stroke SMI workbook during the focus group discussions with the HCP and patients with stroke participants, a number of themes developed. In the first category, being 'General Workbook Layout', five themes arose. The first three themes identified by the researcher, being 'Content structure', 'Colour scheme', and 'Sequence of information', translated across both groups of participants and all relate to the design of the workbook that required adaptation. All the Bridges stroke SMI workbooks are professionally designed to ensure that the content structure, formatting, and layout follows best practices to afford the user the best experience. The fourth theme, being 'Workbook binding', was identified whereby the participants felt the binding used for the workbook was good and appropriate, with several benefits to sticking with that binding method. The fifth and final theme of this category, being the 'Orientation of the workbook', found participants holding differing opinions. However, the argument for the workbook to remain in landscape format was identified by the researcher to be most appropriate; as the orientation can function in conjunction with the content to further benefit users.

In the second category, being 'Workbook Content', a further five themes were identified by the researcher. Themes one and two found consensus between all participants as it related to the variety of stories and the importance of including a vignette that depicts a young patient with stroke. The third theme however noted opposing views between the HCP and the patients with stroke with regards to the vignette content. The HCP participants argued that the stories included in the workbook reflected a first world country and did not reflect the South African culture

enough to be applicable to this setting; and the patients with stroke had the opinion that the stories were appropriate and relatable to them. Theme four found further consensus between the two groups of participants in their views on the appropriateness of the pictures included in the workbook; with both groups indicating the importance and relevance they had to ensuring the user was able to relate to the story content to achieve the desired effect on improving the individual's self-efficacy. Theme five again found consensus between the participants in their views of the need to include a 'Stroke education' chapter in the workbook to help the user understand why they have been impacted by a stroke, and to educate them on how to prevent further strokes in the future.

In the third category, being 'Workbook User-Friendliness', three themes were identified. Theme one involved the appropriateness of the language implemented in the workbook, which was noted by the participants as being simple, user-friendly, and easy to understand for patients with stroke. Theme two discussed the use of the navigation tabs in the workbook; with the participants highlighting the appropriateness of the tabs, but that the workbook and patients with stroke would benefit from the tabs being cut-out for easier navigation of the various chapters. The third and final theme in this category focused on the orientation of the vignettes and the continuation of the stories throughout the various chapters of the workbook; with differing opinions noted between the participants and groups.

The fourth category, being 'Implementation of the SMI in SA Context', identified three themes. Theme one noted the benefits of the workbook, as highlighted by both groups of participants, taking the South African context into consideration. Two main benefits were highlighted, with the first being that the Bridges SMP and SMI workbook could assist in reducing the current dependence that patients have for healthcare provision by healthcare professionals; and secondly, through the general motivational aspect of encouraging patients with stroke to attempt to be more independent and participate more actively in tasks, thereby reducing participation restrictions and the subsequent burden of care on the community. Theme two discussed the need for appropriate HCP training on the self-management programme (SMP) to ensure the fidelity of the SMP and SMI remained throughout implementation. Consistency in skill, and the HCP's attitude, in delivering the SMP and SMI workbook as a tool were noted as being vital.

The third and final theme noted the potential barriers to the implementation of a SMP and SMI of this nature; with the different cultural values, lower literacy rates, and a healthcare resource constrained environment potentially playing a role in negatively impacting on the outcome of the SMI implementation in the South African context.



CHAPTER FOUR

BUILDING SOUTH AFRICAN VIGNETTES

4.0 INTRODUCTION

This chapter describes the third phase of the study, and unpacks the third objective, namely: 'To explore the experiences of South African patients living with a stroke for the purpose of inclusion in the adapted and contextualized South African Bridges stroke SMI workbook'. The 'Background' of the objective is explored first; with the brief 'Methodology' section following; the 'Results' that were obtained are then presented; with the subsequent 'Discussion' being explained; and finally, the chapter ends with the 'Summary' of the objective.

4.1 BACKGROUND

As can be seen in the following literature, stroke and its clinical presentation is common throughout the world; however, how patients with stroke experience living with their disability, and manage in their environment post stroke, is highly dependent on a number of environmental factors, such as: access to healthcare services, physical and environmental barriers, as well as culture, psychosocial, and attitudinal aspects.

According to the World Report on Disability (WHO, 2011), although disability is a universal experience with economic and social costs to individuals, families, communities and nations; a person's environment has a huge effect on the prevalence and extent of the disability experienced. Furthermore, the impact of environmental factors on disability are multifaceted, and variable around the world; often associated with other social phenomena, such as poverty (WHO, 2011). Disability, and the disability experience, varies greatly according to a complex mix of interactions between health conditions, environmental factors and personal factors, including age, sex, stage of life, exposure to environmental risks, socioeconomic status, culture and available resources – all of which vary markedly across geographical locations (WHO, 2011). Therefore, if the experience of disability is variable and directly influenced by the specific environmental context in which the individual with disability is; it stands to

reason that personal experiences of living with stroke would be variable and context dependent too. Al-Oraibi et al. (2011, p.74) confirmed this point, highlighting the difference between experiences of living with stroke in high income and low-to-middle income countries, “where social and economic situations differ in significant ways”; and added further, “in developing countries, the health and social services that are available to patients with stroke, and other people with severe disability, are extremely under-developed”. Therefore, understanding that the lived-experiences of individuals with stroke differs between high income countries, such as the United Kingdom where the Bridges stroke SMI workbook originates, versus low-to-middle income countries, like that of South Africa where the workbook is being adapted and contextualized for, is imperative.

A patient with stroke in a low-to-middle income country, such as South Africa, may find it hard to relate to a patient with stroke they perceived to be from a different background and environment, such as those seen in high income countries like United Kingdom; as described in the following literature. Freeme et al. (2014, p.69) cited literature, stating that, “the average South African stroke patient may present differently from the average British patient, as the majority of South Africans still face challenges such as extreme poverty, lack of basic resources (e.g. running water and electricity), and the effect of HIV/AIDS on stroke presentation and prognosis (Fritz, 2006)”; adding that, “addressing functional activities such as collecting water from a distant source is a different challenge experienced to a stroke patient in England learning how to drive again. South African patients are often unable to attend out-patient therapy due to the lack of public transport for disabled persons, and due to the low socio-economic situation of disabled persons, private transport is most often not an option in the South African context” (Freeme et al., 2014, p.69).

Transport difficulties for patients with disabilities in low-to-middle income countries was confirmed as an important barrier in this context through a study conducted by Urimubenshi et al. (2011), that explored the experiences of patients living with a stroke in a low-to-middle income African country. Urimubenshi et al. (2011, p.398) presented international literature highlighting various environmental barriers experienced by patients living with stroke in more high income countries; stating that, “these barriers could be divided into physical, social and attitudinal environmental barriers”. The

physical environment barriers described issues such as: “inaccessible entryways, bathrooms, and transportation systems; with key barriers including door thresholds and lack of handrails (Hammel et al., 2006)”; and, “negotiating stairs and narrow doorways (Reid, 2004)”. The reported social environmental barriers experienced by patients with stroke included, “having little social support from friends owing to stroke-related disability and having a limited social network (Ekstam et al., 2007)”. Finally, the attitudinal environmental barriers include: “negative behaviors, such as stigma towards the stroke patient (Hare et al., 2006)” Urimubenshi et al. (2011, p.398-399). In the low-to-middle income country, corresponding barriers to that of the high income country were present in terms of social, physical and attitudinal; but with varying degrees. Urimubenshi et al. (2011) concluded by stating that a number of environmental factors can affect a patient with stroke’s ADLs and social participation; with the barriers experienced limiting their reintegration and having an impact on the patient’s overall experience of their stroke.

One further factor that has a significant influence on a patient’s experience post stroke is their cultural identity as discussed in the following literature. In South Africa, Wegner et al. (2015) identified supporting research that indicated that attitudes of society, as well as practices and ideologies (cultural identity), are central environmental barriers to patients with stroke in rural areas (Maart et al., 2007). Further to this, MacLachlan (2006) recorded that societal perceptions, practices and ideologies form the basis of cultural beliefs; which define who people are, how they experience the world, and how they behave in certain situations. Wegner et al. (2015) highlighted further evidence that culture plays a central role in health-related behaviours through studies by Carroll et al. (2007) and Omu et al. (2012); concluding that different cultural groups have vastly different perceptions of the causes of disability and disease; and that these perceptions influence their experiences and health-seeking behaviour.

Based on the above literature, as well as the feedback received from the local South African neurological rehabilitation healthcare professionals and local patients with stroke in Chapter 3; the researcher concludes that depicting the specificity of local South African environmental factors and experiences of patients living with stroke, through the vignettes included in the adapted and contextualized South African Bridges workbook, is key to ensuring that the target South African stroke population is

able to effectively relate to and benefit from using the intervention. Therefore, it is imperative to get appropriate and authentic South African vignettes to include with the international vignettes to ensure a more relatable product is produced.

4.2 METHODOLOGY

4.2.1 Population and Sampling

The researcher initially intended to produce ten South African vignettes for the purpose of inclusion in the draft South African Bridges stroke SMI workbook; but as a result of the feedback received from Phase 1 and 2, it was found to not be necessary to remove all the United Kingdom (UK) vignettes. The new South Africa Bridges stroke SMI workbook therefore aimed to have ten vignettes in total; made up of five appropriate original UK vignettes, and five new South African vignettes. The sampling frame for this part of the study, to acquire the five South African vignettes, was the LEIC and BMH discharge registry. A purposive sampling method, using the criteria as described in Chapter 2, section 2.3.2, was employed on patients with stroke who had been living with stroke in the areas of Mitchells Plain and Philippi for more than six months; and who were easily accessible (Suen et al., 2014).

According to the Census 2011 report, Cape Town had a population of around 3.78 million people; of which 310 485 people lived in Mitchells Plain, and 200 603 people in Philippi. Mitchells Plain has a total of 67 993 dwellings, with 94.9% living in formal dwellings; whereas Philippi has a total of 64 411 dwellings, with only 43.6% living in formal dwellings, and the rest living in informal. Both communities represent a population with low higher-education levels at 5.9% for Mitchells Plain and 3.9% for Philippi. The representation of household amenities in Mitchells Plain for piped water inside the dwelling (95.9%), electricity (99.3%), and a flush toilet connected to sewerage pipes (95.5%) are all relatively high; whereas in Philippi, the representation of households with available amenities for piped water inside the dwelling (26.7%), electricity (84.5%), and a flush toilet connected to sewerage pipes (75.3%) are significantly lower (Statistics South Africa, 2018).

These two communities, urban Mitchells Plain and peri-urban / rural Philippi, are within close proximity to the research setting; and are representative of the nearly 36% of the general South African population living below the poverty line of R3 500 per month

(Statistics South Africa, 2018), having exposure to significant environmental barriers to post-stroke participation restrictions. As such, patients with stroke from these two communities were identified by the researcher as meeting the inclusion criteria for this study. Table 4.1 below depicts the socio-demographics of the participants included in this phase.

Table 4.1: Socio-demographics of Phase 3 participants

Participant	Gender	Age	Ethnicity	Diagnosis
1.	Male	37	Black	Left CVA
2.	Female	47	Coloured	Right CVA
3.	Female	49	Coloured	Right CVA
4.	Male	65	Coloured	Left CVA
5.	Male	73	Coloured	Left CVA

4.2.2 Research Instrument

The research instrument used in Phase 3 to explore specific experiences of living with a stroke in South Africa, described in Chapter 2, section 2.4.2, is an interview guide, with 12 open-ended questions, and several sub-questions, to explain broadly their experiences of living with a stroke (Annexure N).

4.2.3 Data Collection Procedure

The LEIC and BMH discharge registry was reviewed by the researcher, and five potential patients with stroke who were living in the community for at least six months at the time of data collection were purposively selected by the researcher for potential inclusion in the study. These potential participants were contacted telephonically by the researcher, or the trained research assistant, and invited to participate in the study. An appointment was made to meet with participants who agreed to participate in the study, at their place of residence at a time that was convenient for each of them. Each participant was first presented with an information sheet from the researcher, which detailed their specific involvement in the study. Thereafter, the purpose of the study was comprehensively explained to them by the researcher; and informed consent was then requested.

To explore the individual's experience of living with a stroke in detail, the interview started with a broad question, namely: "Tell me about yourself before the stroke; what did you like doing, what were you good at, can you give examples of things you have done in the past which have gone well, or you have overcome?"; this was followed up by the following questions: "How did you feel when you first learnt that you had a stroke?"; "Can you give some idea of how you manage day to day at the moment"; "Can you tell us a bit about what happened to you, what you have been through, and some of your ups and downs?"; "Some people have stressed the need to get away from thinking about their health condition all the time, how do you do that - what works for you?"; "What is a small thing that makes a big difference to your life living with a stroke - how do you maintain being you?"; "How do you maintain or build relationships with family and friends - How do you interact with people?"; "What do you think about the support you have living in Cape Town, are there groups, clubs or support that you think is unique to here?"; "Can you give us any examples of the targets or steps you have set which have worked or haven't worked?"; "Lots of people like to have a list of hopes and dreams, is there anything that's really important to you which might take a bit of time, but you want to try and do?"; "How do you cope when you have lots of visits from healthcare staff, it can get overwhelming for some people - do you have any tips or ideas for others going through the same?"; and finally, the researcher ended the interview with the question: "What's the one thing you would like to tell someone in your position, such as a bit of advice, an idea, or a tip?"

The data was collected using in-depth, semi-structured, one-on-one interviews and captured via audio recording by the researcher, or the trained research assistant, depending on who was present for the interview. After permission was granted, photographs were taken of each individual performing general exercises, such as walking and upper limb exercises, and activities, such as household tasks or leisure activities; as well as photographs of the surrounding environment, which were also obtained during this time for inclusion in the workbook.

4.2.4 Data Analysis

The data from the interviews in Phase 3 was collected via an audio recording device, used by the researcher and research assistant; as well as field notes that were taken during the discussions. The audio recorded data was transcribed verbatim by an

independent transcriber, who is fluent in English and Afrikaans, the two languages used during the interview process. Translation of the Afrikaans transcripts to English took place by the research team for the purpose of data analysis and theme identification. To prevent bias from occurring during this process, and throughout all phases of this study, the interview process and transcriptions were done by two different individuals.

For Phase 3 of the study, an inductive thematic analysis procedure, as described by Braun et al. (2006) in Chapter 2, section 2.6, was employed to analyse the qualitative data collected from the participants. Trustworthiness of the data obtained in Phase 3, was achieved again by ensuring that the standards of credibility, transferability, dependability and conformability were met (Shenton, 2004). Credibility was attained by making it clear to participants that their participation was voluntary, and that they had the right not to participate, thus the use of informed consent forms. Further credibility was obtained through the use of verbal probes, by the researcher, during the semi-structured interviews to get the required data from participants so that the questions were answered effectively. Finally, credibility was achieved through the use of a member checking process, described in Chapter 2, section 2.7.1; by the researcher engaging with the participants during the interview to confirm the points that were being made. Transferability and dependability were obtained through detailed provision of information about the study under investigation, including a comprehensive methodology and adequate information regarding fieldwork sites. Lastly confirmability was obtained by the researcher keeping an audit trail of the processes followed; making it possible to trace the course of the research step by step through the decisions made and procedures described.

4.2.5 Ethical Considerations

Ethical considerations were applied throughout as indicated in Chapter 2, section 2.8.

4.3 RESULTS

A total of five South African patients with stroke were recruited for this phase of the study. The qualitative data obtained through the interviews held with the South African patients with stroke, which focused on their experiences of living with a stroke in South Africa, is presented below according to the seven themes identified. Refer to Table 4.1

above for the description of the participants in this phase. Table 4.2 below depicts the overall themes to be presented and discussed throughout the remainder of this chapter, including the theme number, name, and sub-themes.

Table 4.2: Themes identified during interviews in Phase 3.

Theme Number	Theme Name	Sub-Theme
1.	Active lifestyles	
2.	Different post-stroke experiences	
3.	Family support	
4.	Common challenges	
5.	Self-management strategies	Confidence
		Positivity
		Resilience
6.	Small goals	Start somewhere
		High hopes
7.	Stroke support	

4.3.1 Themes

Theme 1 – ‘Active lifestyles’

Each participant had a different perspective to offer about their lives pre stroke, but one common thread was that each led an active lifestyle. The active lifestyles were displayed in different ways for each participant, as illustrated in the quotations below.

One such way the participants were active was through leisure activities, such as: dancing, outdoor activities, reading, cooking, socializing, singing, driving and participating in organized Big Walks.

“I like going out, like dancing, and outdoor activities” - Participant 2.

“I like reading, cooking, socializing with friends, dancing, and playing dominoes” - Participant 3.

“I like singing and instruments; I play the guitar, lead guitar. I was active doing all my own driving” - Participant 4.

“I did a lot of these (Big) walks” - Participant 5.

Work activities, including teaching others, and working around the house, was also a significant aspect highlighted by the participants as contributors to them leading an active lifestyle.

“I was busy with kids, school-going kids; I was teaching them cultural dance, visual art, and performing art” - Participant 1.

“I was very active, meaning work, work, work; no rest” - Participant 2.

“I did a lot of work myself - I even painted my roof and did gardening, and also helped my wife” - Participant 5.

Finally, providing a service to others was noted by the participants as further ways they were active in their lifestyle.

“I looked after a paralyzed woman for five days of the week” - Participant 3.

“I was very active in the church - I am a pastor; speaking to and visiting people” - Participant 4.

Theme 2 – ‘Different post-stroke experiences’

The different post-stroke experiences depicted by the participants, detailed first-hand the type of anxiety and stress related to this traumatic event. Some participants were able to deal emotionally and psychologically with the trauma; while others had difficulty coping. The quotations below highlight the negative feelings participants held initially, with a poor outlook on their condition.

“That day when I had the stroke, now I am feeling like I am a bit slowed. You can’t do a lot of things that you used to do... You are restricted to certain things; I tried myself

to do all those things, but it is just like you have been cut off from certain things. I was very emotional. I was crying, crying, asking questions, why it happened to me and I am still emotional about it. To me it was my fault, because I was ignorant (to my health condition), that was the thing - So ignorance was my problem. I did not want to take good care of my health” - Participant 2.

“I was quite worried (after the stroke); because, (I asked myself) ‘what’s going to happen to me now?’ I saw a lot of people who got strokes; here in our vicinity, one of our friends, she’s got a stroke - She can’t walk. I wanted to know, how did it happen? Why did it happen to me? - I was an active person” - Participant 5.

As seen in the quotations below however, some participants were able to negotiate the traumatic event of their stroke with the initial negative feelings participants held shifting towards a positive outlook on their condition.

“I was lying in bed. I wanted to wake up to pee, but I could not stand up. I turned to this side, but it was difficult. Then I tried this side, it was still difficult - And then I fell down. My speech started to change. Something had changed, I realised. I could not speak properly. I was surprised until I was told by the doctors what caused stroke. Then I started getting comfortable when I knew what was happening after that” - Participant 1.

“It was like a tremor to me; so, then I told my wife, ‘Oh, here is something coming’. I tried if I can avoid it, but there was nothing to avoid... and I felt a bit scared. After the stroke, well then I realized, I have lost the one side... (thinking to himself) ‘okay, now I will probably have to sit with it’ - Well actually, they say you can be healed from it (stroke); it is not a permanent thing”. Also, “I am a very positive guy, according to my belief; and for me it is, ‘I am going to lift myself out of it’, the stroke must not conquer me, I want to conquer the stroke - that is how I felt” - Participant 4.

Theme 3 – ‘Family support’

Participants expressed that they received support from various sources post stroke. These included immediate family and, in particular, their spouses, were highlighted as

a common trend that played in integral part in supporting them through the effects of the stroke.

“My family; but the big part is played by my girlfriend, because we have an 11-year-old son - they support me” - Participant 1.

“Support from my family, because the thing is, (before the stroke) they always ran to me. I was like the pillar - my mother, my sisters, my children, my husband; everybody comes to me, ‘I want this’, ‘I need that’, ‘won’t you do this for me?’” - Participant 2.

“The main person (who supported me) is my wife - she was a hundred, more than a hundred, percent behind me; it is as if she had a stroke, that is how she actually supported me” - Participant 4.

“I got enough support (after the stroke); especially from the wife. She’s the one that’s very supportive of me” - Participant 5.

Theme 4 – ‘Common challenges’

Participants highlighted a number of post-stroke challenges, with each having a different viewpoint to offer on what affected them mostly in their particular environment and situation. The common theme however, was clear that all patients with stroke, to some degree, suffer the commonality of post-stroke challenges in their everyday lives. The quotations below highlight the challenges raised by the participants, including: difficulty with completing basic and instrumental activities of daily living, as well as extending these activities for a prolonged period; participation in community and social activities; and, financial difficulties resulting in limited access to transport. The challenges impacted negatively on their activities of daily living and participation in the community; and reflected the day to day lives of these patients living with stroke in South Africa.

The following quotations highlight the challenges experienced with basic and instrumental activities of daily living in and around the home; as well as in needing to maintain or extend an activity for a longer time.

“Where I stay, the challenge is to get water and to go to the toilet, because these two are far from the house, but I try to go there myself. I manage to clean the house; but what is difficult is to do the washing. It was difficult to walk a long distance. I was a little bit scared. To do things on my own was a bit difficult. To light a stove and make myself food was difficult” - Participant 1.

“I am slowed down, and I am trying to go, be there again (making food and doing the washing) – it will take time” - Participant 2.

“I can’t stand very long to do the washing and wash up” - Participant 5.

Participation in community or social activities is a challenge that faces patients with stroke on a daily basis, which negatively impacts on their quality of life and creates a perceived burden for the patient’s support system, as seen in the below quote.

“Most of the time I would like to go out, but then I think, you can’t go just anywhere you want to go; (I think to myself) ‘Are you going to be a nuisance to other people?’ - You must plan” - Participant 5.

Financial difficulties, and subsequent challenges with transport, was also expressed by the participants, which impact negatively on the patient with stroke’s ability to attend out-patient treatment appointments.

“I remember I skipped (physiotherapy session) the one month, because we didn’t have finances to go; it is a distance from us” - Participant 4.

Theme 5 – ‘Self-management strategies’

The participants highlighted their individual views on what allowed them to overcome and manage well post stroke. All viewpoints provided surrounded the concept of ‘Self-management strategies’; with three sub-themes, that have close ties to self-management, being presented under this overarching theme, including: ‘Confidence’, ‘Positivity’, and ‘Resilience’.

The quotations below provide strategies, as it relates to self-managing one's health condition, from one patient with stroke to another; with the first strategy to ensure compliance with medication and rehabilitation appointments.

“They must take medicine properly and visit (their) physiotherapy sessions. They must not dodge those two – the treatment of stroke and physiotherapy sessions. They play a very good role, because they teach you how to do things on your own, how to wash yourself, how to make tea for yourself, and how to cook” - Participant 1.

Further strategies from the participants advocating for self-management highlighted the importance of patients with stroke attempting to do things for themselves.

“You must lift yourself out of the situation; whenever a person tells me something about stroke and ‘you must do this, and you must do that’, I tried - I always tried to do it and then sometimes it worked. They must do their physio, they must do their homework, that is the main thing” - Participant 4.

“I think, they must try to help themselves. Don't just sit there or lay there - Try to do something for yourself. We were at the hospital and this nurse came and she said to me, ‘Do you want me to wash you?’. I said, ‘I've been washing myself all the years, I'm going to do it’. I did wash myself - I wasn't that good, but I tried it...You must try and do something for yourself, even if it's just washing your face, or washing your arms. Do something for yourself to give you more confidence that you can do these things; otherwise, nobody's going to help. They trying to help you, but you the one that must always help yourself” - Participant 5.

‘Confidence’

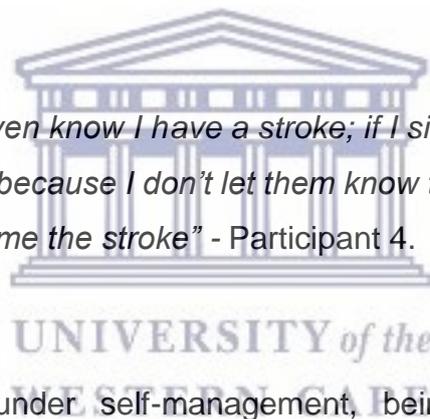
The first sub-theme, being confidence, also considered as self-efficacy, to achieve as set goal or task, is a core component of self-management. Feedback from the participants highlighted a clear theme of needing to have confidence in yourself and in how you present yourself to others; and putting yourself in situations where you have the opportunity to socialize. The quotations below highlight the importance participants placed on socializing; and how they managed to have confidence in themselves to achieve this.

“That’s one of the ways (socialising) that make me survive every day. Interacting with people makes me to be better than yesterday” - Participant 1.

“When people come around, my neighbours, they come, and they talk to me. It is good to have people to talk to sometimes, strangers, not actually strangers but not your immediate family” - Participant 5.

“The friends that I have, they were very supportive - they don’t look at me as (a person with a stroke), they treat me the same way. When I came home the first time, I was actually ashamed, because I walked with a stick and I didn’t want the people to see me like that; but then afterwards, I realized, why do I have to be ashamed, because they treat me as normal as it could. I came out and then they looked at me, and they said, they can’t believe that I had a stroke, because the way I am presenting myself” - Participant 2.

“What I do - people don’t even know I have a stroke; if I sit like this and talk to people and they won’t even know, because I don’t let them know that I had a stroke. To me it is that I am going to overcome the stroke” - Participant 4.



‘Positivity’

The second sub-theme under self-management, being ‘Positivity’, is another component closely linked with the concept of self-management. The participants were unanimous in terms of their views on the need to maintain a positive mindset post stroke. The quotations below highlight the strategies used by the participants to remain positive, such as: the individual with stroke viewing themselves as normal, not thinking negatively about situations, setting a daily routine, trying to do things independently, and spirituality. The first strategy implemented by the participants was to ensure they had a positive mindset about their approach to the achieve their goals.

“Most of the time I’m with people. I attend church services and community events. I don’t think about those things (my condition post stroke) - I still see myself as a normal person just like before. I always associate my mindset with what I want to do. If I want to go to the church, my mind goes for that. I’ll wake up, wash myself, and go to church. I don’t think negatively. If I’m unable to dress myself, I must wait for assistance. I

always go against the thoughts that say I can't do certain things...I suggest people not to entertain thoughts that defy who they are. One must follow the thoughts that are positive. If you told yourself you're going to be fine, that is going to help you a lot. The negative thoughts that say it is over, stress you a lot to a point there will be no progress in your life. Those negative thoughts should be discarded. If you take good suggestions from people - that helps a lot" - Participant 1.

"I just keep a positive mind. I am in a routine at the moment - my mind is already set up in that routine; I am actually more disciplined now. You have to be disciplined, because I do not want to have another stroke again" - Participant 2.

"Be sure to be positive. You need to help yourself. Try if you have to do something" - Participant 3.

"I want to be as I was before. I am a very religious person; I dreamt that I am out of my stroke, I walked, and I said, 'Oh wow, there is nothing wrong with me'. These things come because I am positive" - Participant 4.

The quotations below speak to the importance of facing reality, talking about your feelings, and not shying away from the situation as another strategy employed by the participants to remain positive.

"I know I had a stroke - I never hide away from it because, if you hide away, it will just get worse" - Participant 5.

"You must look after your health, take it slowly, day by day. You will get there, at the end of the day...Talk about it (your stroke), because I have got a neighbour who also had a stroke and it is important to be on that level, where you can talk about it. Do not keep it in because, I mean really it is going to eat you up if you do not talk about your emotions" - Participant 2.

'Resilience'

The third sub-theme under self-management, being resilience, again is a closely linked component of self-efficacy and therefore, of self-management. With the post-stroke

challenges in mind, the participants highlighted some ways they got around their particular challenges. The responses were varied according to the specific challenge discussed, but the trend leaned towards the participant requiring, and employing, a certain level and sense of resilience to overcome the challenge.

The quotations below highlight several strategies employed by the participants when overcoming hurdles in the face of challenges; including asking for assistance, prayer, practicing certain difficult tasks, and taking initiative to overcome difficulties experienced.

“It depends what I want to do for myself. I get water into the bath and wash myself. I ask when I need assistance, maybe to tie the shoes and then to wash this side (unaffected side) of my arm. But, I wash the other parts myself” - Participant 1.

“Well first things first, I pray every day, that God helps me, to give me strength, to do the function that I used to do” - Participant 2.

“I could not cut onions. But as I practiced, practiced, practiced - it became better. Now it's no longer a problem to cut onions or vegetables. The more I practice, the better it will be. The more you do, the better” - Participant 3.

“In that month (that we skipped the physiotherapy session), believe me, I did not leave everything as it is; I practiced every day, I did my physio every day. Even if I, I must teach myself, I will do it” - Participant 4.

“Sometimes, I don't want to do things. I just feel like I'm tired, I don't want to do it. But then, after a while, I just do the things - I force myself sometimes to do things” - Participant 5.

Theme 6 – ‘Small goals’

The participants highlighted ways that made a big difference in their post-stroke situation; with their responses holding a common theme of maintaining their focus on achieving ‘Small goals’, with small victories as the focus. A sub-theme, which can be

closely linked with setting small goals, is also presented below under the heading 'Start somewhere'.

The quotations below highlight the small goals that patients with stroke set for themselves, such as completing a small task of daily living independent of any help; and seeing progress in their level of independence of a task, such as walking.

"The small thing in my life is if I can do certain things; because when I discovered, I can cut the onions, you have to keep this hand, you have to use your knife, when I discovered, 'My word, I can do it', you know how I felt? It is like, I did the most impossible things. I thought to myself, I am going to walk by myself. So true as a Living God, I walked up that stairs alone and I walked down alone, and I felt so good, because I thought I couldn't do it - the impossible, I make it possible" - Participant 2.

"I am watching the progress and I can see it happen; like there was a time in my life that she (physiotherapist) had to hold me, and I had to hold onto her, and for me, (after) I don't hold on to her anymore. So that tells me, that I am not there (at that level of dependence) anymore, I am here" - Participant 4.

'Start somewhere'

When the participants discussed what small steps or targets they set for themselves to get through each day or week; their responses highlighted a common theme with regards to needing to just try and start somewhere. The quotations below described strategies for how the patients with stroke approach their day and week; with examples of achieving one task at a time, and not just sitting idly but rather attempting to keep busy around the house.

"For instance, I'll wake up, wash myself, make food, clean the house, tidy up the yard, and then go wherever I feel like going to" - Participant 1.

"For my mindset was, I can't just sit, I have to try to do what a woman should do at home. The first thing I tried was to help my daughter - so the one day I tried to hang up the washing, and she was quite surprised when she saw me; and then I tried to do the dishes and she sent a message to her friend, 'My mommy is trying to clean, helping

me cleaning the house'. It is the small things that I tried to make her life easier and not to be a burden. I wanted to be independent, I wanted to do things, I do not want to be a burden on my family - That is why I took small steps of doing things" - Participant 2.

"My steps was this - I need to get moving because I can't just sit here. I have to go to start to do something for myself; I can't depend on my family all the time, because, they also need that time to relax" - Participant 5.

Theme 7 – 'Stroke support'

A common theme surrounding the lack of accessible stroke support groups in the community was made abundantly clear to the researcher, as seen in the quotations below; with concerns being raised regarding the few groups that may be available, which are far away, and transport is required to access them.

"I think they are existing for people who have my illness in certain parts of town. I have heard of those groups, but I have not yet attended them – I would need transport" - Participant 1.

"If you go out to your home, there is nothing (post-stroke support). Where I am, I know, I am the second stroke survivor where I stay. There is nothing for us, so you have to do it yourself" - Participant 2.

"There are no more groups that I know. But here are a lot of people who had a stroke" - Participant 3.

"Nothing, because I am always trying to find out, who had a stroke and what did they do to overcome it and all that" - Participant 4.

"There's no clubs that I know of" - Participant 5.

Theme 8 – ‘High hopes’

All participants still held high hopes when discussing what they still wanted to achieve post stroke; with the quotations below highlighting focuses such as returning to driving, work, and walking independently again.

“My wish was to build a centre to keep out-of-school under-age children”; and, “I want to drive a car, but it’s difficult” - Participant 1.

“The things that I have achieved so far is tops; but there are other things that I still try to do (work), but I will prevail” - Participant 2.

“I just want to go to work, that’s all” - Participant 3.

“To walk normally, driving, and play the guitar. I feel I am going to be normal and I work towards it and achieve it” - Participant 4.

“The thing that I really like to achieve again is to walk; to do these Big Walks because I was very proud of my wife and myself” - Participant 5.



4.4 DISCUSSION

The original UK Bridges stroke SMI workbook, as described in Chapter 1, section 1.1.5, consists of eight sections that the researcher will reference during the discussion below, as to how the various themes identified in this phase relate to the sections of the workbook. From the interviews conducted with the participants, seven themes and five sub-themes arose that were identified as being significant in the context of this study for achieving the objective of exploring the experiences of South African patients with stroke; so as to build contextually relevant vignettes and content for inclusion in the draft South African Bridges stroke SMI workbook. The themes, summarized in Table 4.2, were presented with the relevant supporting quotes in the Results chapter above, and will be discussed further below.

The first presented theme, being ‘Active lifestyles’, provided key insights into the lives of the participants pre stroke, with the overwhelming commonality being that each was,

in their own way, active through either leisure-related activities, such as: dancing, outdoor activities, reading, cooking, socializing, singing, driving and participating in organized Big Walks; or work-related activities, including: teaching others, working around the house, and providing a service to, or caring for, others. The first theme of 'Active lifestyles' flows into the second identified theme, highlighted as, 'Different post-stroke experiences', which emphasized that stroke does not occur in one particular way, or affect an individual in the same way as it does another. More importantly, it depicted the misunderstandings patients with stroke have; whereby the participants couldn't understand why the stroke had happened to them as they had led an active lifestyle prior. According to (McDonald, 2008), risk factors to stroke, as described in the introductory Chapter 1, section 1.1.1, are numerous and not often found in isolation; and, although physical inactivity is one such risk factor to the development of stroke, there are numerous other factors that may play a key role in the eventual occurrence of a stroke. Furthermore, risk factors only raise a person's risk for having a stroke, they do not make a stroke inevitable. It is possible to have multiple risk factors and never experience a stroke, or conversely, a person can suffer a stroke without having obvious risk factors (McDonald, 2008). The above findings corroborate the feedback obtained in Phase 1 and 2; whereby the local healthcare professionals and patients with stroke called for a 'Stroke Education' chapter to be included in the South African Bridges stroke SMI workbook for the prevention of both primary and secondary strokes. The first two themes identified here relate to section 3 of the UK Bridges stroke SMI workbook, namely: 'People living with stroke'; which describes the experiences and progress of individuals after their stroke. Apart from the addition of the 'Stroke Education' section, and adaptation required to the context of the vignettes for the local South African population; the researcher reasons no further adaptations are required for this section of the workbook.

The third identified theme, being 'Family support', provided clarity on the importance placed on immediate support structures for patients with stroke, especially in the aftermath of such a traumatic and tragic event in one's life. Tsouna-Hadjis et al. (2000, p.881) cited dated but relevant literature that indicated, for a patient with stroke, "functional deterioration, major depression, and social disintegration after stroke often interact to reduce life satisfaction (Astrom et al., 1992)"; with extensive evidence existing that, "family members, especially the patient's spouse, may offer important

social support (Evans et al., 1990; Lehmann et al., 1975; Shapiro, 1983; and Bishop et al., 1983), instrumental help (Pilisuk et al., 1986), emotional encouragement, and compliance with rehabilitation prescriptions (Reiss et al., 1986); because patients with stroke themselves are usually dependent, disabled, or both. Similarly, a non-supportive family context may be associated with non-adherence to treatment recommendations (Evans et al., 1987; and 1990), and with poorer outcomes (Evans et al., 1987; Strickland et al., 1981; and Gresham et al., 1979)” Tsouna-Hadjis et al. (2000, p.881).

The findings from a longitudinal study conduct by Tsouna-Hadjis et al. (2000) on 43 first-time patients with stroke, to identify the role of family support on the psychosocial status of patients with stroke, corroborated and strengthened this above cited literature. The quantity of family social support received by the participants was found to be directly proportional to their functional status, as well as their social and depression status, within the first six months after the stroke. The Bridges organization understands the importance of supporting and incorporating the family of patients with stroke in their rehabilitation interventions; and as such, in consultation with family and friends of people who have experienced a stroke, they developed a ‘Family and friends’ booklet to supplement the SMI workbook. The booklet provides guidance from other families about how they have supported their relative or friend to self-manage using the Bridges approach and workbook, as well as general advice and resources for carers. The researcher therefore recommends for future research, the inclusion of an adapted and contextualized South African Bridges ‘Family and Friends stroke booklet’ to supplement the South African Bridges stroke SMI workbook.

‘Common challenges’, highlighted as the fourth theme through discussions with the participants, included a variety of issues, which impacted negatively on their activities of daily living and participation; and reflected the day-to-day lives of these patients living with stroke in South Africa. These challenges encompassed managing the impact of functional impairments post stroke for completion of basic and instrumental activities of daily living, such as: fetching and carrying water, and using the toilet, due to the far walking distance from the residence; washing of clothes; and preparation of food; as well as, extending these activities for a prolonged period. Further challenges highlighted included: participation restrictions for community and social activities; the

increased burden of care on family, and the community caring for the affecting individuals with stroke; and, the financial disparity affecting those individuals with stroke, especially in rural areas, resulting in limited access to transport, and therefore restricted access to healthcare services, such as the clinic or out-patient departments.

South African patients with stroke face these, and a number of other, challenges every day; with the National Census 2011 indicating that, around 13.4% of households headed by persons with disabilities have no access to piped water; and, 45.2% of households headed by persons with disabilities have access to a flush toilet (Statistics South Africa, 2014). This theme relates to the fourth section of the UK Bridges stroke SMI workbook, namely: 'Managing my stroke', which describes common issues that are experienced by patients with stroke, and some individual, personal solutions to managing them. The researcher therefore reasons that the 'Managing my stroke' section of the South African Bridges stroke SMI workbook is a vital component to adapt and contextualise, during this process, to the local challenges experienced by patients living with stroke in South Africa; so as to offer the user relevant advice and ways of addressing or over-coming these challenges.

The fifth theme, 'Self-management strategies', was clearly identified by the researcher in the discussions and feedback received from the majority of participants who referenced this concept in some way throughout their journey. Self-management was clearly noted as being critical to the positive outcome for South African patients with stroke, who attribute much of their success to this way of approaching their daily challenges. The role of self-management in the positive outcome for patients with stroke has been extensively covered by literature in the preceding chapters; particularly Chapter 1, section 1.1.5; whereby it was highlighted that engagement in self-management interventions by individuals with long-term chronic conditions, such as stroke, are said to be the key to promoting recovery and clinical outcomes, empowering the individual, having a positive impact on their quality of life, facilitating improved health outcomes and overall healthcare service use (Boger et al., 2012; de Silva, 2011).

Several sub-themes, namely: 'Confidence', 'Positivity', and 'Resilience', were identified in the overarching theme, due to their close interlinks with the core concept within self-management, being self-efficacy. 'Confidence' was noted as a theme with

participants highlighting the importance of patients with stroke having confidence in themselves, and in how they present themselves to others; as well as needing to put themselves in situations where the opportunity exists to overcome challenges. 'Positivity', depicted by the need for patients with stroke to maintain a positive outlook on their situation; focusing on socializing, having a structured routine, spirituality, and not shying away from the effects of the stroke, but rather embracing it and striving to overcome the obstacles. 'Resilience', highlighted the importance of patients with stroke adapting to circumstances, and overcoming challenges that lay ahead. In the feedback from the participants, overcoming challenges took the form of self-reliance or independence, spirituality, mastery of tasks through repetition, and self-discipline; all of which rely heavily on the individual having a strong and positive mindset.

Confidence in self, the power of positivity, and resilience in the face of challenges are all interlinked to, and important components of, self-efficacy; the cornerstone of the Bridges self-management concept (Riazi et al., 2014), which has been covered previously in Chapter 1, section 1.1.3. Self-efficacy, a psychological construct and mediator of action (Riazi et al., 2014), is said to determine whether an individual will attempt an action or not, and whether they will persevere in overcoming perceived obstacles (LeBrasseur et al., 2006). Higher levels of self-efficacy are associated with higher performance attainment (Riazi et al., 2014), and a tendency to tackle more challenging tasks, put forth more effort, and persist longer with a particular task in the face of aversive stimuli (Hellstrom, 2002). Ultimately, self-efficacy predicts functional independence and participation post stroke (Riazi et al., 2014). Maujean et al. (2014) concludes that a key factor in determining outcomes once patients with stroke are living in the community is their self-belief about their ability to overcome the difficulties they encounter. Based on the above literature, self-efficacy has been adopted and encouraged throughout the Bridges stroke SMI workbook to promote engagement with activities and limit participation restrictions; which would otherwise ultimately impact negatively on the patient with stroke in their community. This theme and sub-themes are prevalent throughout but relate most closely to the fifth section of the UK Bridges stroke SMI workbook; which focuses on 'Keeping active' and encourages the user to try and do whatever it is they want to do to achieve their personal goals and targets. It also contains examples from the contributors regarding the different strategies used to maintain and enhance functional activity and participation. The researcher therefore

reasons that these ideals should be represented in the South African vignettes included in the South African Bridges stroke SMI workbook.

The sixth theme to be identified, being 'Small goals', was noted by the participants as being important to their motivation and drive to continue their functional improvement. As defined by The National Institute for Health and Clinical Excellence (NICE, 2010) in Chapter 1, section 1.1.4, one of the core components of effective stroke rehabilitation interventions is goal setting; further described in Chapter 1, section 1.1.5, as one of the core self-management skills required to achieve effective self-management in individuals (Lo et al., 2013). Lenzen et al. (2017, p.2) cited literature stating that, "depending on what is important to the patient, goals for the patient's self-management can be set and actions can be planned (Bodenheimer et al., 2007)"; furthermore, "within the primary care sector, the term 'collaborative goal setting', defined as a process in which healthcare professionals and patients agree on health-related goals, is frequently used (Bodenheimer et al., 2009)". Rice et al. (2017, p. 857) identified that, "the benefits of goal setting have been consistently demonstrated in the literature", citing that, "patient participation in goal formulation has been shown to have beneficial effects, resulting in the development of personally relevant goals, as well as greater satisfaction with the rehabilitation experience overall (Holliday et al., 2007)"; and that, "stroke survivors who achieve their rehabilitation goals are less likely to be depressed, demonstrate stronger self-efficacy beliefs, and have more positive perceptions of their participation within the community (Brock et al., 2009)".

Two sub-themes, which can be closely linked with setting of goals, was also identified within this overarching theme under the headings 'Start somewhere', and 'High hopes'. The first sub-theme, 'Starting somewhere', was identified with the participants stressing the need to add value in the lives of the people around them, in their homes, and in their community again, so as to feel valued and be less of a burden on others. This, according to the participants could be achieved through taking the first small step or just trying and starting somewhere so as to be in a position to build on the successes achieved. The second sub-theme, being 'High hopes', was noted by the researcher through discussions with the participants about their future desires to still achieve certain goals. Understandably, the main hope highlighted by the participants was as a result of their desire to return to their previous lifestyle; in such that they wanted to

return to their baseline functioning, or what they perceived as being 'normal' for them – e.g. driving, working, walking. Soundy et al. (2014, p.1) observed that the most recognized and accepted definition of 'hope' is from work by Snyder et al. (1991), stating that, "hope is a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal directed energy), and (b) pathways (planning to meet these goals)". Soundy et al. (2014, p.1) cited several pieces of literature stating, "the term hope has been used to describe how a person tries to balance their present situation with better expectations in their future (Olver, 2005). Hope is considered to be a key element in the recovery process (Bright et al., 2011), and influences motivation and goal achievement in rehabilitation (Snyder et al., 2006). Research suggests patients draw on hope as a natural response to the experience of chronic conditions, such as stroke (Bright et al., 2011). Therefore, hope serves as an important coping mechanism in the face of a crisis (Wiles et al., 2008) and plays an important role throughout patients' rehabilitation, particularly when progress is slow (Folden, 1994)". This theme and sub-themes relate to the sixth and seventh sections of the UK Bridges stroke SMI workbook, being 'Future goals' and 'Control now' respectively. 'Future goals' encourages the user to plan for the future and hold onto their hope so as to motivate them; and, 'Control now' aims to encourage the user to take control of the situation they find themselves in and choose goals of personal value. Based on the above, the researcher reasons that the importance of this section of the workbook is vital to the delivery of the overall self-management concept and intervention; and therefore, that the section should remain unchanged in the South African Bridges stroke SMI workbook.

The seventh and final theme, being 'Stroke support', was an important finding in the overall discussions with the participants in this phase; as they have been in the community for some time after discharge from supportive environments, seemingly into communities with little to no external or organized support groups other than the informal support received from neighbours suffering from similar conditions. According to the Heart and Stroke Foundation of South Africa (2018), there are monthly regional meetings held for individuals who have suffered from cardiovascular diseases, such as stroke, at major hospitals in Cape Town, Durban, Port Elizabeth, and Johannesburg respectively; but taking into account the challenges faced by the patients with stroke, this monthly arrangement may not be sufficient or effective. Bryer et al. (2010)

emphasized that an effective stroke service requires the establishment of a seamless network consisting of acute stroke units, post-acute care and rehabilitation, as well as further care in the community; but that the problems of limited infrastructure and shortage of staff still need to be addressed at national, provincial and district levels. This theme relates to the final section of the UK Bridges stroke SMI workbook, being 'Useful contacts', which offers the user contact details of local organisations to support their continued functional improvement in the community. The researcher therefore reasons that useful contacts for the local stroke population should be included in the South African Bridges stroke SMI workbook; and that the above revelations go a long way to strengthening the call for the implementation of self-management interventions in the community, that can be effective in encouraging self-reliance independence, rather than a need for external support or dependence.

4.5 SUMMARY

From the results of this phase, seven overarching themes were clearly identified as being integral to the journey of South African patients with stroke. The first presented theme, being 'Active lifestyles', provided key insights into the lives of the participants pre-stroke, with the overwhelming commonality being that each was, in their own way, active though either leisure-related activities. The second identified theme, highlighted as, 'Different post-stroke experiences', emphasized that stroke does not occur in one particular way, or affect an individual in the same way as it does another. More importantly, it depicted the misunderstandings patients with stroke have; whereby the participants could not understand why the stroke had happened to them as they had led an active lifestyle prior to it. The third identified theme, being 'Family support', provided clarity on the importance placed on immediate support structures for patients with stroke, especially in the aftermath of such a traumatic and tragic event in one's life. 'Common challenges', selected as the fourth theme through discussions with the participants, included a variety of issues, which impacted negatively on their activities of daily living and participation; and reflected the day-to-day lives of these patients living with stroke in South Africa. The fifth theme, 'Self-management strategies', was clearly identified by the researcher in the discussions and feedback received from the majority of participants who referenced this concept in some way throughout their

journey. Self-management was clearly noted as being critical to the positive outcome for South African patients with stroke, who attribute much of their success to this way of approaching their daily challenges. Several sub-themes, namely: 'Confidence', 'Positivity', and 'Resilience', were identified in this overarching, due to their close interlinks with the core concept within self-management, being self-efficacy. The sixth theme to be identified, being 'Small goals', was noted by the participants as being important to their motivation and drive to continue their functional improvement. Two sub-themes, which can be closely linked with setting of goals, was also identified within this overarching theme under the headings 'Start somewhere', and 'High hopes'. The first sub-theme, 'Starting somewhere', was identified with the participants highlighting the need to add value in the lives of the people around them, in their homes, and in their community again, so as to feel valued and be less of a burden on others. The second sub-theme, being 'High hopes', was noted by the researcher through discussions with the participants about their future and desires to still achieve certain goals. The seventh and final theme, being 'Stroke support', was an important finding in the overall discussions with the participants in this phase; as they had been in the community for some time after discharge from supportive environments, seemingly into communities with little to no external or organized support groups other than the informal support received from neighbours suffering from similar conditions.

All the identified themes in this phase obtained from the experiences of South African patients with stroke related to aspects of the Bridges SMP and SMI workbook, either directly in the workbook itself, or indirectly, such as in the case of theme three, 'Family support', with the need for the support of a Bridges 'Family and friends' stroke SMI booklet. The included South African patients with stroke vignettes and content should therefore be representative of the themes discussed above.

CHAPTER FIVE

ADAPTATION AND CONTEXTUALIZATION

5.0 INTRODUCTION

This chapter describes the final two phases of the study; and unpacks the fourth objective, namely: 'To identify aspects of the original UK Bridges stroke SMI workbook that requires adaptation and contextualization for the South African stroke population'. As with the previous chapters, the 'Background' of the objective is explored further first; the brief 'Methodology' of processes are explained; the 'Results' obtained during the process are highlighted; the subsequent 'Discussion' is presented; and finally, the chapter ends with the 'Summary'.

5.1 BACKGROUND

As highlighted in Chapter 1, section 1.2, proof of concept for the Bridges SMI workbook was identified through research to be beneficial and acceptable from the perspective of patients with stroke, caregivers and healthcare professionals; with positive effects reported on the participation of patients living with stroke in the UK (Jones et al., 2009, 2016; & McKenna et al., 2013, 2015). However, as alluded to, the SMIs are context specific and need to be culturally acceptable for effective implementation (Cha et al., 2012). Hale et al. (2014) explained that the Bridges stroke SMI workbook was originally developed in close consultation with patients who had experienced a stroke in the UK; and that its cultural sensitivity had not yet been fully explored. Due to the potential benefit the Bridges stroke SMI workbook had to improve participation restrictions in patients living with stroke, Hale et al. (2014) conducted research whereby the original UK Bridges stroke SMI workbook was successfully adapted and contextualized for the New Zealand context.

Prior to the start of this research study, the researcher hypothesized that a stroke SMI workbook could have similar beneficial and positive effects in addressing participation restrictions experienced by patients living with stroke in the Western Cape, South Africa. The restrictions in question, include those discussed previously in Chapter 1,

section 1.1.2.3; whereby South African patients with stroke are unable, or have a reduced ability, to return to participation in social and leisure activities, work activities, and attend to family responsibilities respectively; with further reports of problems with relationships or feelings of isolation post stroke (Rouillard et al., 2012). Furthermore, as highlighted in Chapter 1, section 1.1.2.2, for South African patients with stroke, Rhoda et al. (2011) identified that travelling on public transport was experienced as an activity limitation; however, this activity limitation has a significant impact on the level of participation of the affected individual as use of public transport is a key component for many of the South African population.

As previously mentioned in Chapter 3, section 3.1 however, Perrin et al. (2006) cautioned against the direct replication of successful self-management interventions (SMI) with populations that are outside of the population context originally used in the successful SMP trials or studies. With this in mind, the researcher of this study had an important decision to make in terms of the approach to take for the implementation of the UK Bridges stroke SMI workbook in a context and environment in which it was not developed for. The following article supports the decision made by the researcher to adapt and contextualize the UK Bridges stroke SMI workbook for the local stroke population.

A South African article, written by Dizon et al. (2016), identified that clinical practice guidelines (CPG), which are similar in nature to that of the SMI in focus for this study, are hugely influential in their role of improving healthcare practices and outcomes; as they assist necessary stakeholders to make evidence-based, informed healthcare decisions. However, Dizon et al. (2016) noted that CPGs are frequently used outside of the context in which they were developed, more so in low- to middle- income countries, which calls into question their relevance.

One option available to countries is to develop their own CPGs to meet the identified need. However, Dizon et al. (2016) states that the development of these new guidelines can be expensive and time-consuming; and requires knowledge, skill and expertise, which can be limited in low- to middle- income countries. As is often the case though, Dizon et al. (2016) notes that CPGs developed in these countries have compromised quality and credibility due to the urgent need for evidence-informed and cost-efficient healthcare; and as such, these newly developed CPGs can fail to meet

the required standards. A second option to creating a new CPG is however available to stakeholders, as highlighted by Dizon et al. (2016), using a process of either adopting, contextualizing, or adapting exhibiting CPGs to suit the local need. Dizon et al. (2016) outlined four steps to determine the need for developing new CPGs, or identifying an alternative, as depicted in Figure 5.1 below.

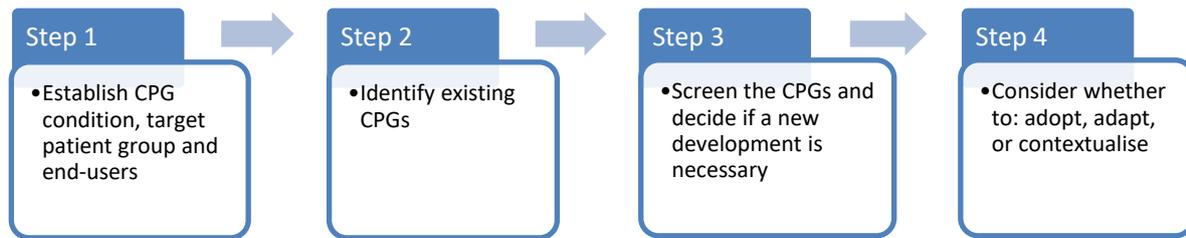


Figure 5.1: Four steps in determining the suitable approach to CPG development (Dizon et al., 2016)

Dizon et al. (2016) noted that it is justifiable to use a current and good quality CPG; and decide whether to adopt, contextualize or adapt the content thereof. The researcher in this study identified that the UK Bridges stroke SMI workbook was current and of good quality for implementation to address concerns of the local stroke population; however, that adaptation and contextualization was required to ensure suitability in the local context.

The importance of contextualizing the concept and approach to self-management in the specific environment in which the SMI is to be employed should not be underestimated; a point heeded by Hale et al. (2014). As previously highlighted, self-efficacy influences the initiation of an individual's behaviour change, and as such has been implemented as the cornerstone of SMIs (Riazi et al., 2014); and that self-efficacy can be influenced both positively and negatively, by four factors, namely: "mastery experience, vicarious experience, verbal or social persuasion, and somatic and emotional state" (Malouff, 2013, p.13). With these working principles in mind, influencing one's self-efficacy requires that the individual be actively engaged with, and able to relate to, the content available; whereby the content is perceived by the user as being similar in nature to their personal situation. Therefore, as it relates to this study, it is imperative the users of the South African Bridges stroke SMI workbook

are able to identify with the included content, such as the vignettes and pictures, implemented. Failure to achieve contextual relevance with the environmental and or contextual nature of the South African workbook has the potential for sub-optimal outcomes; as patients with stroke would not be able to actively engage with the perceived foreign content or relate their specific situation to that seen in the vignettes and pictures; limiting the impact on their level of self-efficacy, and therefore reducing the overall benefit achieved from the SMI. Therefore, to ensure the best possible outcome for this study, the work of Hale et al. (2014), as described in Chapter 1, section 1.3, was employed as the conceptual framework for the approach to this study.

5.2 METHODOLOGY

5.2.1 Population and Sampling

5.2.1.1 Phase 4 – Expert Panel

An expert panel was established by the researcher in Phase 4, using purposive sampling (Suen et al., 2014; Dudovskiy, 2016; and Crossman, 2017), for the purpose of reviewing and commenting on the adapted and contextualized draft South African Bridges stroke SMI workbook. This panel was made up of an 'expert international support research team' including: the UK Bridges programme founder and director, Professor Fiona Jones; as well as Professor Leigh Hale, the principle researcher who successfully adapted and contextualized the original UK Bridges programme for the New Zealand setting.

5.2.1.2 Phase 5 – Healthcare Professionals

Convenience sampling was employed for recruiting available neurological rehabilitation healthcare professionals (HCPs) as participants into the study during the fifth phase (Suen et al., 2014; Dudovskiy, 2016). All members of the multi-disciplinary rehabilitation team responsible for the rehabilitation of patients with stroke at both Life Esidimeni Intermediate Care (LEIC) and Booth Memorial Hospital (BMH) were conveniently selected to participate. The HCPs from LEIC included in the study consisted of eight participants, comprised of: two Physiotherapists, two Occupational Therapists, a Social Worker, a Speech and Language Therapist, a Dietician, and a Registered Nurse; while the HCPs from BMH consisted of four participants, comprised

of: one Physiotherapist, one Occupational Therapist, a Social Worker, and a Registered Nurse. In total, for the fifth phase of this study, 12 healthcare professionals were included. Table 5.1 below depicts the designations of the fifth phase HCPs across the two facilities.

Table 5.1: Designation of the Phase 5 participants

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

5.2.2 Data Collection Procedure

Stage one of the adaptation and contextualization process of the original Bridges stroke SMI workbook, which encompasses Phases 1, 2, and 3 of the study, and is previously described across Chapters 3 and 4, was done by the researcher and his co-researcher; and, was based on the data obtained from the views of both the healthcare practitioner participants in Phase 1, and the patients with stroke participants in Phase 2, through the use of FGDs regarding the implementation of the Bridges stroke SMI workbook in the local South African setting; as well as making use of the data collected in Phase 3, through the use of one-on-one interviews on the experiences of South African patients living with a stroke. Findings from these three phases were first reviewed and analysed by the researcher and co-researcher for

theme identification, using a deductive approach to thematic analysis procedure in Phases 1 and 2, and an inductive approach in Phase 3 (Braun et al., 2006), agreed upon, and then presented to the research supervisor. Thereafter, the first draft South Africa Bridges stroke SMI workbook was developed for presentation to the expert research team, as described in the second stage below.

In the second stage of the adaptation and contextualization process, being Phase 4 of the study, the researcher invited the 'expert international support research team', to be participants of the research as part of an expert panel. The researcher first explained the study and objectives to the individuals in this expert team; thereafter, data collection occurred through the use of a document review process (Department of Health and Human Services, 2009), whereby the expert panel was tasked with critically reviewing and providing individual general comments to the researcher on the appropriateness and applicability of the draft South Africa Bridges stroke SMI workbook. After reviewing the draft, the experts documented their responses electronically to the researcher. Findings from Phase 4 were reviewed by the researcher and co-researcher, changes agreed upon, and then presented to the research supervisor for discussion. Thereafter, the draft South Africa Bridges stroke SMI workbook was further adapted accordingly to produce the final draft South Africa Bridges stroke SMI workbook, for presentation to the local neurological rehabilitation healthcare professionals, as described in the third stage below.

In the third and final stage of the adaptation and contextualization process, being Phase 5 of the study, the researcher sought to consult the local neurological rehabilitation healthcare professionals on their views of the final draft South African Bridges stroke SMI workbook for implementation in the local context. The researcher followed the same recruitment process employed in Phase 1 of the study; whereby the researcher verbally invited the HCP at BMH and LEIC to participate in the study. Each participant was first presented with an information sheet, in the language of their preference (Annexures A, B, C), from the researcher, which detailed their specific involvement in the study. Thereafter, the purpose of the study was comprehensively explained to them by the researcher; and informed consent, in the language of their preference (Annexures H, I, J), was then requested. The participants were then issued with a copy of the final draft South African Bridges stroke SMI workbook to review for

one week. The researcher gave instruction to the participants to review the workbook with the four main areas that was under investigation in mind, namely: “General Workbook Layout”, “Workbook Content”, “Workbook User-Friendliness”, and “Implementation of the SMI in the South African Context”.

The HCPs were then invited to participate in a focus group discussion (FGD) that occurred one week after they had been issued with the workbook. The two FGDs with the HCP participants were conducted in English, at LEIC and BMH respectively, using the FGD interview guide (Annexure M) in the format of an in-depth, open-ended, and structured interview conducted by the researcher and a trained research assistant, at a time that was convenient for the participants (Zhang et al., 2009). Both FGD took place according to the recommendations of Krueger et al. (2015) and Krueger (2002). Prior to the start of the FGD, the participants were requested to sign a ‘focus group binding form’ (Annexure K, L), whereby the participants committed that the information discussed in the focus group would be kept confidential and would not be discussed outside of the focus group. Each FGD took approximately 30 minutes to complete.

5.2.3 Data Analysis

The data from the expert panel in Phase 4 was collected electronically, via email responses to the researcher. The data from the FGDs in Phase 5 was collected via an audio recording device, used by the researcher and research assistant; as well as field notes that were taken during the discussions. Transcripts were made of the audio recordings. To prevent bias from occurring during data collection throughout all phases of this study, the FGDs and transcriptions were done by two different individuals. The audio recorded data was transcribed verbatim by an independent transcriber, who is fluent in English, the language used during the FGD, for analysis of common themes by the researcher. A deductive thematic analysis procedure (Braun et al., 2006), was employed to analyse the qualitative data collected from the focus groups in Phase 5.

Trustworthiness of the data obtained was achieved by ensuring that the standards of credibility, transferability, dependability and conformability were met as described by Shenton (2004) in Chapter 2, section 2.7. Credibility was attained by making it clear to participants that their participation was voluntary, and that they had the right not to participate, thus the use of informed consent forms. Further credibility during the FGDs

was obtained through the use of verbal probing by the researcher, in response to the answers given by the HCPs, to get the required data from participants so that the research question was answered effectively; and through informal member checking, whereby the researcher confirmed the information the participants were providing to ensure what was being said was what was intended. Transferability and dependability were obtained through detailed provision of information about the study under investigation, including a comprehensive methodology and adequate information regarding fieldwork sites. Lastly confirmability was obtained by the researcher keeping an audit trail of the processes followed; making it possible to trace the course of the research step by step through the decisions made and procedures described.

5.2.4 Ethical Considerations

Ethical considerations were applied throughout as indicated in Chapter 2, section 2.8.

5.3 RESULTS

The data obtained from the expert panel in Phase 4, on the first draft of the South African Bridges stroke SMI workbook, is presented below first; followed thereafter by the data obtained from the local neurological rehabilitation healthcare professionals in Phase 5, on the final draft of the South African Bridges stroke SMI workbook. It is important to note that there was a process of adaptation, from first draft to final draft of the South African Bridges stroke SMI workbook between Phases 4 and 5; whereby the workbook was adapted further based on the feedback received by the expert panel.

5.3.1 Phase 4 – Expert Panel

5.3.1.1 UK Bridges Director

The feedback received from the UK Bridges Director, on the first draft of the South African Bridges stroke SMI workbook, detailed a number of valuable points that required careful consideration and attention by the research team.

Due to copyright regulations, the first point cautioned the team on the use of generic images in the workbook that were not owned by the researchers themselves.

“If you use any images/logos that are on the web you will need to get permission; so, it might be better for the designer to reproduce the images - if someone sees an image you have used without permission there will be big costs attached (we have been stung before!)”.

The second point highlighted that the images used in the workbook should be of a high quality to produce the best result.

“The photographic images all need to be of high quality otherwise they will appear pixilated - when the draft goes to the designer its better if the photos are all in a separate folder rather than embedded on the document”.

The third point encouraged the use of the traditional South African rainbow colour scheme throughout the workbook.

“I like the photos of SA and wonder whether the colour scheme could be rainbow throughout - as long as the Bridges logo and recognition of the IP is somewhere that would be fine with us - as the look has to be right for SA”.

The fourth point advised the research team to limit the use of the word 'expert' in the advice section of the workbook so as to allow for a feeling of the workbook being from the patients rather than healthcare professionals.

“I wouldn't use the 'expert physio' advice too much, but show to as many stroke patients as possible; the idea of it being theirs and feeling as if it's a useful tool is most important”

The fifth point explained the most practical way of finalizing the draft workbook before final printing to ensure that the professional developer would have all the right components to put together the final copy of the workbook.

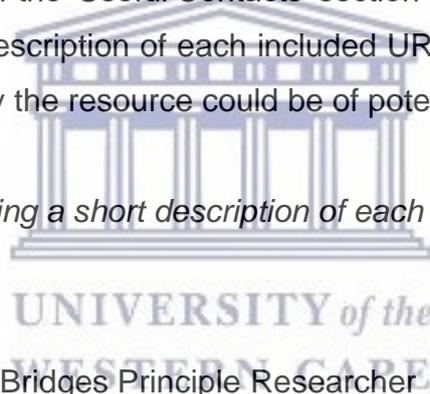
“The next steps would be to get a final draft of the copy written in a word document; then put all the photos you plan to use in a separate folder with indications as to where they should go - our designer will take it from there. But it’s much better to read, read and read again the copy as once she produces a PDF proof is harder to start making big changes”.

The sixth point concerned the correct use of wording in the workbook for the documentation of the intellectual property to ensure that all the appropriate stakeholders receive the necessary recognition.

“We will need to agree on the wording regarding IP and recognition of all the contributors - we always name each stroke survivor, etc. that have been involved.”

Lastly, recommendations for the ‘Useful Contacts’ section of the workbook were made around the inclusion of a description of each included URL to ensure the user had a better understanding of why the resource could be of potential benefit to them.

“Finally, I would advise having a short description of each key contact rather than just the URL.”



5.3.1.2 New Zealand Bridges Principle Researcher

The feedback received from the New Zealand Bridges principle researcher, on the first draft of the South African Bridges stroke SMI workbook, highlighted a number of valuable points that required careful consideration and attention by the research team.

The first point raised highlighted two limiting areas of the workbook. The first limiting factor raised focused on the issue of diversity, both with regards to the vignettes’ level of functioning, as well as ethnicity.

“Although you have diversity, it seemed that all your participants were more mildly affected (physically at least) and you had no “severe disability” story; so, someone less able might not think it was a workbook for them. Also, wondered if you needed another Black story to be more representative”.

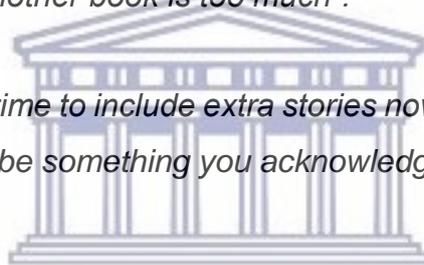
An important comparison between the draft South African workbook and the New Zealand workbook was drawn, with respect to the vignettes being unrepresentative of the total stroke population of the area; but offered a recommendation to address the concern.

“Our NZ workbook is very unrepresentative of many cultures, including Pacific and Asian, and could have more North Island Māori stories, and we are often criticised for that.”

The New Zealand Bridges principle researcher explained that under-representing a culture or lacking diversity in the vignettes of the workbook is not a simple fix, highlighting that it costs both money and time to correct.

“The expense of creating another book is too much”.

“Of course, you won’t have time to include extra stories now - they take ages to recruit, interview, edit etc.; but maybe something you acknowledge in your limitations section of your discussion.”



However, a potential solution was offered should under-representation occur, by indicating that more diverse online content could be made available to patients with stroke that address the gap without incurring the cost of continual redevelopment of the workbook.

“But I do wonder if we could continue to create stories for a website or app that people could go to find someone more like them?”

The second limiting factor raised on the area of the workbook not be fully representative of certain stroke clinical, functional, and participatory presentations.

“Some of the ability / participatory limitations of stroke are not presented (again just something to note in limitations) – e.g. pain, balance, intimate relationships”

A further positive comment was however noted on the movement of the 'Reflection' chapter from the start of the workbook to the end.

"I like how you have done this section with not only noting what progress they have made but also how they got there".

The final comment questioned the rationale behind the language the workbook was being implemented in; with a further query as to the whether or not the workbook would be translated into the other official languages of South Africa.

"Will you present an argument for which language you will have it – or are you thinking of translating?"

5.3.2 Phase 5 – Local Healthcare Professionals

The qualitative data obtained through the follow-up FGD held with the HCP participants focused on their views as they relate to the implementation of the final draft South African Bridges SMI stroke workbook in the local context; and is presented below according to the nine themes highlighted across the four main categories of the discussion, namely: "General Workbook Layout", "Workbook Content", "Workbook User-Friendliness", and "Implementation of the SMI in the South African Context". Refer to Table 5.1 above for the description of the HCP participants used in Phase 5. Table 5.2 below depicts the nine overall themes to be presented and discussed throughout the remainder of this chapter, including the theme category, theme number and theme name.

Table 5.2: Themes identified during HCP FGD in Phase 5

Theme Category	Theme Number	Theme Name
General Workbook Layout	Theme 1	Workbook guidance
Workbook Content	Theme 1	Use of wording
	Theme 2	Vignette variety

	Theme 3	Functional level disparity
	Theme 4	Patients' wording
	Theme 5	Young vignette
	Theme 6	Picture usage
Workbook User-Friendliness	Theme 1	Workbook design
Implementation of the SMI in the South African Context	Theme 1	Education and social support barrier

5.3.4.1 General Workbook Layout

Within this category, one main theme, being 'Workbook guidance', was identified by the researcher and presented below.

Theme 1 – Workbook guidance

This theme focuses on the perceived inadequate provision of sufficient guiding instructions for effective use of the various workbook chapters. When the participants were asked about the general layout of the workbook, there was agreement that there were good aspects to the layout of the information provided in the draft South African Bridges stroke SMI workbook; but that the introductory sections of the chapters lacked sufficient guiding information for the user to use the material effectively, as seen in the quotations below.

"With regards to the intro ... I just thought it wasn't as detailed as it could have been"
– LEIC Healthcare professional.

"I really like that it said there is no right or wrong way to use the book; but then maybe an additional section just to give a bit more prompting" – LEIC Healthcare professional.

"It's nice you can use it (the workbook) for a higher functioning or a lower functioning (patient); but maybe with a set of specific ideas on how to use it – (i.e.) 'If you are having difficulties with this, specifically focus on these (vignettes)' or 'Read through this person's (vignette)' / 'Read through a person's story a day'. Just some ideas, because I think people, especially stroke patients, with such a thick book - it could be

quite overwhelming. Make it specific for that person...Or a little bit more guidance basically” – LEIC Healthcare professional.

“Because it is a lot of information, what can happen is, especially with a stroke patient, to read through all of that they are not necessarily going to get to the story that is going to be valuable for them, because they might lose attention by the second or the third page” – LEIC Healthcare professional.

“It is really great that it (the workbook) is open-ended, because it lends itself to anywhere you want to use it; but...if you have no guidance, sometimes people are a little bit too nervous to even start because their creative ability has already been hampered; and if they weren’t naturally a creative person before, it is quite a novel task without guidance.” – LEIC Healthcare professional.

5.3.4.2 Overall Workbook Content

Within this category, six themes arose. The first theme identified by the researcher and presented below focuses on the ‘Content wording’ throughout the draft workbook. The second theme touches on the appropriateness of the overall ‘Vignette variety’. The third theme exposes a perceived ‘Functional level disparity’ of the included workbook vignettes. The fourth theme touches on the use of ‘Patients’ wording’ verbatim verses being censored by the researcher. The fifth theme focuses on the appropriateness of the ‘Young vignette’ inclusion in the workbook. The sixth and final theme highlights the ‘Picture usage’ within the workbook.

Theme 1 – Content wording

When the participants were asked about the overall workbook content, a common theme presented itself between the two focus groups. The quotations below highlight the concern regarding the excessive, and aphasia-unfriendly, use of wording for the content in the draft workbook.

“From a speech therapist point of view...sometimes it (the workbook) was quite wordy...some people might potentially have aphasia...So something to just consider,

there are aphasia friendly principles which you might be able to bring in - using bigger text...Wide open spaces and things like that that could potentially make it easier...not like big, long sentences, but sometimes like key points” – LEIC Healthcare professional.

“For me, there is too much writing for most of the speech therapy patients” – BMH Healthcare professional.

Theme 2 – Vignette variety

With regards to the variety of the presented vignettes in the draft workbook, both focus groups agreed and highlighted, as seen in the quotations below, the diversity and representative mixture of the South African population as it relates to the culture, the various age groups, and the perceived socio-economic statuses.

“There was a mixture of stories and different ages, and different sort of cultural backgrounds with different classes; it is really nice how it spanned across sort of the whole South Africa” – LEIC Healthcare professional.

I really like that there were stories from lots of different patients and I think it seems like quite a diverse collection; different ages, different socio-economic groups, so it is a nice diversity” – BMH Healthcare professional.

As there were a few HCPs in the group who were also present for the first FGD on the original Bridges SMI stroke workbook, the researcher posed the question of whether there was a noticeable difference in the cultural representation of the draft South African Bridges stroke SMI workbook verse the original workbook. The response was very positive as seen in the quotation below.

“Significant difference...Much better...because there was, there was different classes, there was different age groups, which the other one did have different age groups as well but it wasn't South African...it was very much incorporating, very diverse” – LEIC Healthcare professional.

The below quotation highlighted the potential cross-over for use of the workbook in the private rehabilitation sector as well, allowing for all patients with stroke, regardless of demographic, to feel like part of a whole community.

“In terms of having the different cases or patients... from different backgrounds, it is quite nice; so, if you may be in a private sector, you can see what other people are dealing with and vice versa...You are part of the community.” – LEIC Healthcare professional.

However, it is important to note that the BMH HCP focus group identified that the draft workbook vignettes were perhaps over-represented with regards to ethnicity, and not necessarily sufficiently varied, as seen in the below quotation.

“A lot of coloured patients that they presented in here, but there is only one black guy...maybe they should have just gotten more variety of patients...A better, wider spectrum of different cultures” – BMH Healthcare professional.

Theme 3 – Functional level disparity

While discussing the overall workbook content, the two focus groups emphasized a common point surrounding the fact that the included vignettes were of mostly a higher level of functional ability. The quotations below highlight the perceived disparity in the functional levels of the included vignettes; and that lower functioning patients with stroke, using the workbook, may find more value in identifying with vignettes depicting a patient with stroke who is more dependent in their mobility and activity levels, but still coping and participating in their community.

“From the patients that I saw, most of them were more higher functioning...It would have been nice (to include a lower functioning person), because even though a patient may feel, ‘Okay, I don’t have functional use of my upper limbs...I am still independent” – LEIC Healthcare professional.

“I wonder if it is not worth having just another lower functioning (vignette), or either in an informal settlement and a lower functioning person, and how independent they are

in an informal settlement...to show also that - that some people don't get that full independence, but that they can still cope and participate in life... regardless of whether or not they are physically independent” – LEIC Healthcare professional.

“It is very positive, and I imagine that is the aim of the book, but I think so many of our patients lose a lot of functions...I don't know if this book necessarily has enough examples of the limitations that you face after a stroke” - BMH Healthcare professional.

“It is really motivating for the patients and the things that they found that helped them; but, I am sure there is a whole group of patients (lower functioning) that haven't been touched...That haven't really progressed. So, it might be nice to have sort of both sides; maybe a bit more focus also on the challenges” – BMH Healthcare professional.

Theme 4 – Patients' wording

The LEIC HCP focus group discussed and debated how best to present the vignette content in the workbook by either using the patient's words verbatim, as they said it in their respective interviews, verses being censored and adapted by the researcher to be more grammatically and phonetically correct. The quotations below describe the thought processes of the participants, and the eventual agreed upon outcome of using the participants words verbatim in the workbook content.

“A few grammar (changes)... And especially where, well most of it is where the patient talks; I didn't think we need to write word for word what the patient (says)” – LEIC Healthcare professional.

“I don't think so though, as long as you put it in quotations, if the patient says, like in our South African context, if a patient speaks that type of Afrikaans that has that... ‘Mengels’....and there is like sounds that come through that is not appropriate, not correct English, I think it is correct because the person identifies...that is how the person speaks to us...because it is simple and they can identify” – LEIC Healthcare professional.

“Punctuation is fine to change because the person never spoke with punctuation; you have to keep that (grammar) because that is what tells you that they (the researchers)

didn't just make this up and that this is a true, true experience" – LEIC Healthcare professional.

Theme 5 – Young vignette

When the HCP participants were asked about the which stories they identified as being the most appropriate in the workbook, both focus groups agreed that all the included vignettes were appropriate; but interestingly, the participants were drawn to the young stroke participant, Helen, the most – as seen in the quotations below.

"I think they are each interesting in their own way because they all focus on something slightly different...if I were a patient I would like the one that I identified most with." – BMH Healthcare professional.

"I enjoyed the young one, Helen, that became a physio, I thought that was very positive. It stood out because she still has impairment post stroke; there is still forgetfulness, cognitive fallout, and things like that yet she was able to obtain her degree. So, for me that is motivating for the younger patients." – BMH Healthcare professional.

"The one that struck me as more rare than the others was the twenty seven year old (Helen), but it is not to say we haven't had, we have had young folks so it is really important to have that in there." – LEIC Healthcare professional.

"I quite liked that story, because she was able to return to studies and actually complete a degree, and she is working now." – LEIC Healthcare professional.

"That also stood out for me because she was young and people need to know that it is not just for old people, anybody can have a stroke any time in his life." – LEIC Healthcare professional.

Theme 6 – Picture usage

When the participants were asked about the appropriateness of the pictures in the workbook, the participants were unified in their opinion that the included pictures were useful and helpful to a degree, to add meaning to the content, and to assist with the patients who have difficulty reading - as seen in the quotations below.

“I think the profile pictures of each patient is helpful as sort of a visual aid to help; so at least it almost orientates a little bit, because you have got the name but you have also got the picture of the person. Maybe it makes it, especially if you’ve got cognitive fallout, it makes it a bit more meaningful.” – BMH Healthcare professional.

“I like there is some pictures here...there is pictures of exercises, ADL, hanging up washing, cooking; that is nice, because you can actually then see what the patients are doing.” – BMH Healthcare professional.

“From a visual input towards a patient that may be struggling to read, that is a good sign just looking at her, seeing that maybe I am doing exactly the same exercises so.” – BMH Healthcare professional.

However, as seen in the following quotations below, the participants were reserved in their opinions of how much value the current pictures were adding to the overall workbook, as they were presented.

“There is no real meaning...it is just pictures of the patients.” – BMH Healthcare professional.

“I wasn’t always sure exactly what I was looking at or why they were showing certain pictures” – BMH Healthcare professional.

Point of interest

No further themes were identified by the researcher in the category of ‘Overall workbook content. However, one point of interest raised by a participant during the FGD was around the new addition of the Stroke Education chapter in the draft workbook, as seen in the below quotation.

“I liked the explanation of stroke, it was quite simple...Straightforward” – LEIC Healthcare professional.

5.3.4.3 Work User-friendliness

Within this category, one main theme, being 'Workbook design', was identified by the researcher and presented below.

Theme 1 – Workbook design

This theme focuses on the perceived unprofessional design of the draft workbook; with the quotations below indicating a clear agreement amongst the participants that the draft lacked the required professional touch for the user, especially a patient with a stroke, to use the workbook efficiently and effectively.

“I don't like the fact that there is two columns on each page I just find that, for some patients it is going to be very confusing” – BMH Healthcare professional.

“The colour put me off...I think someone with a visual impairment after the stroke would struggle more” – BMH Healthcare professional.

“The quality of the pictures were poor...I think that the pictures would be very useful if they were laid out properly; I feel like... all different sizes, and they are all over the place, so right now it is just too confusing, I don't think they really add much.” – BMH Healthcare professional.

“On the different pages, the font is different sizes, different line spacing. It is just very confusing; I think for patients that have had strokes it will be just too much - I feel this book would really benefit from having a professional person design it” – BMH Healthcare professional.

5.3.4.4 Implementation of the SMI in the South African Context

Theme 1 – Education and social support barrier

Within this category, one main theme presented itself when the participants were questioned on the viability of implementing a SMI of this nature in the South African

context. Both groups agreed that the workbook would have good potential, if implemented and supported correctly, as seen in these quotations below.

“The idea is a good one I think to give patients ... a little bit of inspiration so that they can see other stories and know that they are not alone; even to write down and kind of monitor their progress. But, like I said already, I think you would really need somebody to work with them” – BMH Healthcare professional.

“English speaking, literate patients, in our local population would definitely (benefit).”
– LEIC Healthcare professional.

However, both focus groups also had their reservations, with similar concerns being shared for the South African population around the barrier of low education and English literacy, and low social support to assist the affected individuals with the implementation; that would ultimately negatively impact on the effectiveness of an intervention of this nature, as seen in the quotations below.

“I think the one thing in South African context is not everyone can read...So there are some people who will be excluded and obviously the language barrier will be another reason so not, it won't, everyone won't be able to use it...and some people have very basically reading ability so it's – honestly the education problem” – LEIC Healthcare professional.

“If I was a stroke patient I would probably look at it every once in a while, just for the cases just as a bit of motivation; but I don't know if I would want to go further with it, because if there is no one there to guide you and to help you, I wouldn't see the need for that.” – BMH Healthcare professional.

5.4 DISCUSSION

The users of the South African Bridges stroke SMI workbook need to be able to identify with the adapted and contextualized content that has been included, such as the vignettes and pictures, to ensure optimal benefit from the intervention. The researcher therefore endeavoured to approach the adaptation and contextualization process of

the workbook for the South African setting is a systematic and careful way, using the work of Hale et al. (2014) as the framework, and a three-staged method.

5.4.1 Stage One

Stage one of the adaptation and contextualization process, to produce the first draft of the South African Bridges stroke SMI workbook involved the review and analysis, by the principle researcher and co-researcher, of data obtained from Phase 1, 2 and 3 of this study. In Phases 1 and 2, 16 themes that were related to the views of the HCPs and patients with stroke on the implementation of the original UK Bridges stroke SMI workbook for the local South African context were identified and discussed in Chapter 3, section 3.5 by the researcher. In Phase 3, eight themes that were related to the experiences of South African patients with stroke were identified and discussed in Chapter 4, section 4.4 by the researcher. The identified themes, as highlighted by local South African neurological rehabilitation healthcare professionals and patients with stroke, who have experienced living with a stroke in the South African environment, were reviewed by the researcher and co-researcher; who then implemented the appropriate changes to the original UK Bridges stroke SMI workbook to produce the first draft of the South African Bridges stroke SMI workbook. The changes that were made, with reasons described in the discussion Chapters 3 and 4, sections 3.5 and 4.4 respectively, surrounded key focus areas of the workbook content. These changes including: 1) moving of the 'Reflection' chapter from the front of the workbook, to the back; 2) usage of five appropriate UK vignettes, and addition of five South African vignettes; 3) inclusion of South African contextually rich and relevant pictures; and 4) addition of a 'Stroke Education' chapter. There were several areas of the original workbook design that were proposed for change but required the intervention of the Bridges professional designer to sign off; and as such, will be sent to the designer as recommendations for the final South African Bridges stroke SMI workbook version. These proposed changes include: hard front and back covers for the workbook, use of rainbow colour scheme throughout the workbook, and cut out navigational tabs. The intention of the first draft South African Bridges stroke SMI workbook was to have a workable product that could be critiqued by the 'expert international research support team' in the second stage of the adaptation and contextualization process.

5.4.2 Stage Two

The data received from the critique by the 'expert international research support team' in Phase 4 on the first draft South African Bridges stroke SMI workbook was aimed at ensuring the draft South African Bridges stroke SMI workbook was peer-reviewed by experts in self-management and stroke SMI workbooks; and was, in the opinion of the experts, acceptable for implementation with the South African stroke population. Feedback received from the Bridges Organization founder and director, and from the New Zealand Bridges principle researcher, of their opinions on the first draft of the South African Bridges stroke SMI workbook, provided important information; highlighting valuable points that required careful deliberation and action by the research team for the production of the final draft South African Bridges stroke SMI workbook prior to consultation with the local neurological healthcare professionals that would take place in Phase 5.

The Bridges programme director focused her comments on the aspects of copyright regulations and permission for use of certain content, such as specific generic images; ensuring intellectual property rights were respected through appropriate wording for stakeholder recognition in the workbook; and, producing a professional product by using their own professional designer to finalize the workbook. These comments are understandable as her role within the organization is first to protect the image and marketability of the brand; limit any potential threat of liability; and, maintain the fidelity of the concept. According to the World Intellectual Property Organization (WIPO, 2018), 'intellectual property' (IP) refers to any new creation of one's mind, i.e. inventions, designs, images, etc.; with copyright an extension of IP, whereby copyright laws provide original creators of content protection for the creations. Furthermore, intellectual property rights allow the creators to benefit from their work. These rights are outlined in Article 27 of the Universal Declaration of Human Rights (WIPO, 2018). (Renner, 2015) stated that it is important that practitioners and developers have a good understanding of what is allowed and not allowed with the product they are developing; with Renner (2015) cautioning that practitioners often find themselves involved in difficult situations that may have legal ramifications. The researcher noted these comments and removed images that permission was not granted for. As for ensuring compliance with intellectual property rights, recognition of appropriate stakeholders,

and producing a professional product; the researcher and co-researcher planned to send the final draft version of the South African Bridges stroke SMI workbook to the Bridges professional designer prior to implementation with the South African stroke population.

The Bridges programme director did however offer several constructive points concerning aspects of the draft South African Bridges stroke SMI workbook that could be adapted by the researcher to make for a more suitable product. The first point was with regards to the quality of the images to be used in the workbook; whereby she encouraged the researcher to rather use images of a higher quality in the workbook to prevent pixilation and a poor end-result. Secondly, the traditional rainbow colour scheme, which had been implemented in one area of the draft workbook, was encouraged throughout the workbook as it is more relatable to South Africa, being the 'Rainbow nation'. Thereafter, use of the word 'expert' in the advice section of the draft workbook was discouraged, as it is contrary to the concept of promoting self-efficacy for self-management in patients with stroke; whereby the users need to view and identify the content as being 'theirs', or from individuals perceived to be in a similar situation as their own, for it to be meaningful and relatable. This point was described by Malouff (2013) previously in Chapter 1, section 1.1.3; whereby to impact positively on a patient's self-efficacy levels, the individual needs to view the subjects being reviewed as being similar to them. Furthermore, with the aim and focus of Healthcare 2030 Road to Wellness in South Africa being to achieve 'A person-centred approach', with a reduction in dependency on healthcare professionals, and greater community involvement in healthcare (WCDOH, 2014); it would be vital to distance the patients from the experts, and therefore to remove tags, such as "expert", in a self-management programme of this nature. Finally, it was highlighted that inclusion of a descriptor along with the website information, under the 'Useful contacts' section of the workbook, would assist the user to have a better understanding of what benefit they could potentially receive by accessing it.

The researcher considered the comments made and attended to each appropriately. The use of the word 'expert' where necessary was limited, and descriptors for the useful contacts section were added. New high-quality images were recommended by the researcher for capture and use in the final version of the South African Bridges

stroke SMI workbook; as well as recommending the rainbow colour scheme to the Bridges professional designer for implementation in the final version.

The New Zealand Bridges principle researcher lauded the draft South African Bridges stroke SMI workbook, indicating that it included excellent stories; and, appreciated the movement of the 'Reflection' chapter to the end of the workbook. However, understandably from her experience of being through this adaptation and contextualization process with the New Zealand workbook, she focused her comments on the content, and the limiting factors that could have a negative impact for the implementation with the local stroke population. Points of concern raised by her were around limited diversity as it relates to the level of functional ability and ethnicity of the included draft South African Bridges stroke SMI workbook vignettes. The concern with the functional level of the current vignettes in the draft workbook were that they depict patients with stroke mainly of a higher level of functional ability; and that patients with a more severe stroke may perceive that the workbook is not suitable for them. Tidy (2017) noted that each person's stroke is different, as are the problems and difficulties faced for each affected person. This point relates to the concept of impacting positively on the user's self-efficacy for self-management. As described by Malouff (2013) in Chapter 1, section 1.1.3, the user needs to perceive that the patient with stroke in the workbook vignette is in similar position to them, or they will not relate to the content; and therefore, will not draw as much benefit from the intervention. Secondly, it was stated that the workbook only contains one vignette of a black individual's experience of living with stroke in South Africa; and that, as this was not representative of the South African stroke population, the workbook would benefit from additional stories including participants of black ethnicity. The comment on the aspect of ethnic diversity was born from experience, comparing the lack of diversity in the draft South African Bridges stroke SMI workbook with that of the New Zealand version; whereby, they often draw criticism for failing to provide sufficient diversity for the New Zealand stroke population. It was further noted that the included content did not cover all clinical, functional, and participatory aspects of stroke.

Countries are made up of individuals from varied national origins, ages, religions, languages, genders, sexual orientations, disabilities, socioeconomic and occupational statuses, and geographical locations, amongst other characteristics; and as such,

Ameritech (2018) stressed that diversity in education is important, regardless of the field of practice, as one size does not fit all. According to Deupree (2018) effective communication of health information to diverse patient populations can assist in improving health outcomes. The researcher therefore notes, with extreme importance, the comments surrounding the limited functional and ethnic diversity, as greater diversity in function and ethnicity of the included vignettes would be more inclusive of the larger stroke population group in South Africa; and improve the relevance and benefit from users engaging with the stroke SMI workbook vignettes.

The New Zealand Bridges principle researcher concluded by questioning the rationale behind the language choice of the workbook, being English; and queried whether it would be translated into the other 11 official South African languages. The benefit to having the SMI workbook in all languages of South Africa is understandable as it would be more inclusive and relevant to more of the local stroke population. English is the language medium in which the original UK Bridges stroke SMI workbook was delivered. Part of the intention for this study and developing the first South African Bridges stroke SMI workbook is to allow for future research to conduct a study to determine whether or not the self-management concept and intervention is viable in the South African context; prior to incurring the costs of translating and distributing the workbook in the other official South African languages. Furthermore, a significant amount of cultural sensitivity would be required in translating the workbook into the other South African languages, thereby confounding the results obtained for the purpose of this study. Also, although English is not spoken by all patients with stroke in South Africa, Alexander (2017) noted that, English is the language mostly engaged with in public life; as well as in government, business and the media, with an estimation that around half the population has a communicating knowledge of the English language. English is also widely used as a second language and common language of communication in South Africa (Alexander, 2018). Furthermore, an article in The South African stated that the latest education curriculum in South Africa makes English one of two languages compulsory at school; with English the language of learning and teaching at most schools and tertiary educations (TheSouthAfrican.com, 2014). The researcher therefore maintains that, for the purpose of this study and the development of the first South African Bridges stroke SMI workbook, that the workbook should be presented in English.

5.4.3 Stage Three

The aforementioned feedback from the experts in Stage two guided further adaptations by the researcher to produce the final draft South African Bridges stroke SMI workbook; which was for presentation to, and consultation with, the local neurological healthcare professionals in Phase 5 through FGDs to understand their views on the implementation of the product and concept in the local context. Nine themes were identified across the four categories in discussion with the HCP participants in the FGDs, and these will be described by the researcher in detail below.

5.4.3.1 General Workbook Layout

One theme in this category, being 'Workbook guidance', was identified as suitable for consideration by the researcher. The HCPs were uniformly of the opinion that the final draft South African Bridges stroke SMI workbook lacked sufficient guiding instructions and directions for effective use of the workbook by the patients with stroke users. The workbook is intended to be a tool that is actively engaged with by the user, and the support system of their family, caregivers or the HCPs if necessary, in a way that empowers their active involvement in their own healthcare and is relevant for them. Too many guiding instructions can stifle the self-management concept as the patient becomes more reliant on the instructions in the workbook, rather than working constructively through the problem they are faced with, applying practically the learnings from the workbook, and asking for assistance from their support system where necessary. This concept is similar in context to that discussed in Chapter 5, section 5.4.2 above around the need to distance the patient with stroke from 'expert' guidance or opinion so as to reduce the dependency that is created in this process. Furthermore, the workbook has an introductory page, called 'How to use this book', with a few small sentences detailing several important points for users to take note of when engaging with the workbook for the first time. The introductory points highlight the purpose of the workbook to the user, explaining that, "People who have had a stroke share their experiences and tips in this book to give you hope, confidence and strategies to live the life you want." Secondly, several points offer some guidance to the users on how to best approach using the workbook, such as: "There is no right way or time to use it"; "Some people begin with the first chapter; others flick through the pages to get an idea of things that might help or interest them"; "Some use the

book on their own; others use it together with their friends and family”; and, “Staff supporting you can give you advice on a place to start or answer any of your questions. Especially if you have difficulty talking, you might find it easier to look through the book with someone”. The researcher therefore reasons that additional guidance, over-and-above the introductory instructions, in the chapters thereafter would be contrary to the intention of the workbook to promote self-management strategies in the users; and, may also further exacerbate the dependency relationship noted for patients with stroke as it relates to professional input or guidance. As such, further guiding information is not for inclusion in the subsequent workbook chapters.

5.4.3.2 Workbook Content

Six themes in this category were identified by the researcher as being suitable, namely: ‘Content wording; ‘Vignette variety’; ‘Functional level disparity’; ‘Patients’ wording’; ‘Young vignette’; and, ‘Picture usage’.

In theme one, being ‘Content wording’, participants, in particular the speech and language HCPs, highlighted that the content of the final draft South African Bridges stroke SMI workbook had an excessive amount of writing and words that were not conducive to patients with stroke; in particular to patients suffering from aphasia. Rose et al. (2011) noted that much of the health information provided to patients with stroke who suffer from aphasia is inappropriately formatted to meet their needs of effective communication. A study done by Rose et al. (2011) on 40 adult patients with stroke offered several valuable characteristics for acceptable and aphasia-friendly health information content delivery: larger fonts, being 14-point or higher, should be used; single font usage; 1.5 line spacing; and liberal use of real photographs, rather than drawings, with included word content. This input was extremely valuable as the researcher, with a physiotherapy background, had no insight into this important aspect of the workbook delivery. The researcher therefore reasons that the final version of the South African Bridges stroke SMI workbook should follow the abovementioned characteristics, as described by Rose et al. (2011), to be relatable and more useable to the stroke population groups with this communication disorder. The researcher will make these recommendations to the Bridges professional designer for the final version of the South African Bridges stroke SMI workbook.

Theme two and three, being 'Vignette variety' and 'Functional level disparity' respectively, was identified as participants from both focus groups were unified in their opinions that the final draft South African Bridges stroke SMI workbook was appropriately representative of a variety of South Africa stroke population groups as it relates to culture, age groups, and socio-economic backgrounds; but not diverse enough with regards to ethnicity and functional level inclusion. The finding of vignette variety correlates with that of the feedback received by the HCP participants in Chapter 3, section 3.5.2 on the appropriateness of the variety of vignettes in the original UK Bridges workbook; and affirms that the researcher maintained the integrity and fidelity of the workbook in the content of the adapted South African version in this regard.

The finding of a lack of diversity among the included vignettes as it relates to ethnicity and functional levels, correlates with the feedback received from the New Zealand Bridges principle researcher in Chapter 5, section 5.4.2, that the final draft South African Bridges stroke SMI workbook vignettes were not necessarily sufficiently diverse enough. Of the included vignettes, only one contained the experience of a South African black patient living with stroke in South Africa; and most vignettes were higher functioning patients with stroke. As stated however in Chapter 5, section 5.4.2, the researcher notes this extremely important gap in the ethnic and functional diversity content of the adapted workbook; which will be noted as a limitation to this study in Chapter 6, section 6.3 for future correction should the South African Bridges stroke SMI workbook be feasible.

Theme four, being the 'Patients' wording', was debated by participants, who deliberated what the best way would be to deliver the vignette content or words used by the South African patients with stroke when explaining their experiences of living with stroke in the workbook. Options for consideration by the researcher were verbatim, as the participants expressed themselves in their respective interviews; verses the content being censored and adapted by the researcher to be more grammatically and phonetically correct. From available literature, Corden et al. (2006) notes that the inclusion of verbatim spoken words and language usage from research participants is becoming standard practice in qualitative research studies. This is as the "inclusion of verbatim excerpts from transcripts of interviews helps to clarify links

between data, interpretation and conclusions, discussed variously within concepts such as validity, reliability, credibility and auditability” (Corden et al., 2006, p. 1).

In a study by Corden et al. (2006), which aimed to investigate the perception of researchers, research users, and research participants on the use of verbatim quotes, it was noted that, users were not certain about what should be done about grammatical mistakes or non-standard spoken English; with a number of components needing to be balanced between readability and accuracy: “some users felt that the diversity of ways in which people spoke brought some of the colour and interest to reports which included quotations” (Corden et al., 2006, p. 19-20). Furthermore, it was highlighted that users liked representation of different kinds of voices; but that grammatical mistakes could be distracting and make reading harder. Some users also indicated that they were likely to make assumptions about social class or educational background of a respondent whose language was shown to include grammatical mistakes; but that, “in some studies, the author might intend such an impact, but unless this was made transparent there could be risks in allowing readers to make their own assumptions” (Corden et al., 2006, p. 19-20). The researcher reasons that maintaining the verbatim wording in the vignette content delivery is paramount to both the quality of the research being produced and the effective user engagement with the workbook.

The fifth theme, being ‘Young vignette’, was identified as participants from both focus groups were again drawn to the young stroke vignette. This correlates with feedback received in Chapter 3, section 3.3.2 from HCPs who also identified most strongly with the inclusion of a young stroke story for the South African stroke population. As with the discussion in Chapter 3, section 3.5.2, whereby the importance of depicting a young vignette in the SMI workbook was strengthened (Bryer et al., 2010); the inclusion of the young vignette in the final draft South African Bridges stroke SMI workbook is affirmed.

The sixth and final theme in this category, ‘Picture usage’, was identified as participants from both focus groups were united in their opinions that, although the pictures in the final draft South African Bridges stroke SMI workbook were useful and helpful to a degree in adding meaning to some of the content of the included vignettes; the participants were more reserved as to how much value the current pictures, as they were presented, were adding to the overall delivery of the content as they seemed

disjointed or to add little meaning. The opinions of the participants were mainly around pictures that had little to no meaning attached to them, or that were disjointed from the surrounding content descriptions. As with the discussion in Chapter 3, section 3.5.2; included pictures should be contextually rich, and allow for the user to interact with the content more effectively (Dietz, 2006). This theme correlates to a degree with the feedback received by the Bridges Director in Chapter 5, section 5.4.2, whereby she indicated that pictures with a higher quality should be used for the South African workbook. Based on these findings, the researcher reasons that new contextually rich pictures of a higher quality should be captured of the vignette patients with stroke and their surrounds for inclusion in the final version of the South African Bridges stroke SMI workbook.

To conclude the discussion on the category of 'Workbook content', the participants affirmed the addition of the Stroke Education chapter to be appropriate and useful for patients with stroke.

5.4.3.3 Workbook User-Friendliness

Only one theme, 'Workbook design' was identified as being suitable for inclusion from this category, by the researcher. This theme highlighted the unprofessional design, namely that of the content layout, the colour scheme, the picture quality, and the varied font size and spacing, of the final draft South African Bridges stroke SMI workbook; with the participants united in their opinion that the workbook lacked the required professional touch for the user, especially a patient with a stroke, to use the workbook efficiently and effectively. This theme matched the views of the expert panel discussed above in 5.4.2, as it related to the need for the final draft workbook to undergo professional design to ensure that it is presented in a way that optimizes its effectiveness on users. However, as discussed in Chapter 3, section 3.5.1, the researcher is aware that all the Bridges stroke SMI workbooks are professionally designed to ensure that the content structure, formatting, and layout follows best practice to afford the user the most benefit. As the design of the Bridges workbooks are handled professionally, the researcher is not able to implement design change, as it relates to content formatting, colour usage, etc. until final sign off from the professional designer; and therefore, the intention of the researcher for this study was not to produce the final version of the South African Bridges stroke SMI workbook; but

rather to produce an adapted and contextualized final draft workbook for presentation to the Bridges professional designer.

5.4.3.4 Implementation of the SMI in the South African Context

Only one theme, 'Education and social support barrier', was identified as being suitable by the researcher in this category. Both groups of participants agreed that the South African Bridges stroke SMI workbook would have good potential in the local context, if implemented and supported correctly by the users' social support system, being their family, caregivers, or HCPs. However, the way in which the implementation occurs, and the support system available to the local stroke population, is perceived by the HCP participants to be the barrier that will limit the workbook's effectiveness in the South African context. With regards to the implementation barrier, it was highlighted that the English language version of the workbook would only be suitable and beneficial for a small population of English-literate South African patients with stroke; but that the majority of the population would not find it useful due to language and literacy barriers. The researcher reasoned in Chapter 5, section 5.4.2 in response to the query by the New Zealand Bridges principle researcher, that the English language usage, for the purpose of this study and process, was acceptable and appropriate to determine feasibility of the concept and SMI workbook prior to incurring the costs of translating and distributing the workbook in the other official South African languages. Further to this, the literacy barrier aspect of the workbook is discussed in Chapter 3, section 3.5.4; whereby the latest literacy figures for South Africa in 2015 place the level of literacy at 94% of the population who could read and write (World Bank, 2018).

The perceived barrier of a lack of user social support systems (i.e. family, caregivers, and under-resourced HCP) for the successful implementation of the workbook in the South Africa context is noted by the researcher as being the area of greatest need. The intervention is such that, without the external support of self-management trained HCP, as well as family or caregivers, being available and able to not only start the process of the SMI workbook, but support its continued delivery, the intervention will not be successful. The researcher however reasons that the intervention, although possibly not suitable for all stroke population groups based on the above barriers, is still suitable for achieving the aim of reducing participation restrictions in patients with

stroke in the Western Cape. Furthermore, small scale feasibility of this concept and stroke SMI intervention could ultimately result in a product that is produced and supported appropriately to meet the needs of the diverse South African stroke population groups.

5.5 SUMMARY

Stage one of the adaptation and contextualization process saw the production of the first draft of the South African Bridges stroke SMI workbook. The changes that were made, with reasonings described in the discussion Chapters 3 and 4, sections 3.5 and 4.4 respectively, surrounded key focus areas of the workbook content. These changes including: 1) moving of the 'Reflection' chapter from the front of the workbook, to the back; 2) usage of five appropriate UK vignettes, and addition of five South African vignettes; 3) inclusion of South African contextually rich and relevant pictures; and 4) addition of a 'Stroke Education' chapter. There were several areas of the original workbook design that was proposed for change but required the intervention of the Bridges professional designer to sign off; and as such, will be sent to the designer as recommendations for the final South African Bridges stroke SMI workbook version. These proposed changes include: hard front and back covers for the workbook, use of rainbow colour scheme throughout the workbook, and cut-out navigational tabs.

Stage two of the adaptation and contextualization process saw the draft South African Bridges stroke SMI workbook being peer-reviewed by experts in self-management and stroke SMI workbook. Feedback received from the Bridges Organization founder and director, and from the New Zealand Bridges principle researcher, of their opinions on the first draft of the South African Bridges stroke SMI workbook, provided important information; highlighting valuable points that required careful deliberation and action by the research team for the production of the final draft South African Bridges stroke SMI workbook. Changes at this stage included: the removal of images that permission was not granted for and ensuring compliance with intellectual property rights; recognition of appropriate stakeholders in the workbook; new high-quality images of the participants were captured for use in the workbook; use of the word 'expert' was limited; and descriptors for the useful contacts section were added. There were several areas of the first draft South African Bridges stroke SMI workbook design that was proposed for change by the experts. The first being the production of a professional

end product; as with stage one feedback, the researcher and co-researcher planned to send the final draft version of the South African Bridges stroke SMI workbook to the Bridges professional designer prior to implementation with the South African stroke population. Secondly, the addition of further functional and ethnic diversity in the included vignettes; which will be noted as a limitation to the study for future correction should the South African Bridges stroke SMI workbook be feasible.

In stage three, consultation with the local neurological healthcare professionals on the final draft South African Bridges stroke SMI workbook highlighted several areas for review prior to the finalization process taking place. Additional workbook guidance, over-and-above the introductory instructions, was noted as being contrary to the intention of the workbook to promote self-management strategies in the users and would further exacerbate the dependency relationship noted for patients with stroke. Content wording needed to be more aphasia-friendly; with the researcher recommending the highlighted characteristics (Rose et al., 2006) to the Bridges professional designer for inclusion with the final version of the South African Bridges stroke SMI workbook. As with the feedback from the experts, the HCPs identified the limited ethnic and functional diversity in the content of the vignettes; which will be noted as a limitation to this study for future correction should the South African Bridges stroke SMI workbook be feasible. Finally, the use of patient words verbatim in quotations was argued for and identified by the researcher through literature to be the most suitable for this study for effective user engagement with the workbook.

CHAPTER SIX

SUMMARY, CONCLUSION, SIGNIFICANCE, LIMITATIONS AND RECOMMENDATIONS

6.0 INTRODUCTION

This final chapter offers a 'Summary' of the study with the main findings highlighted from the previous chapters, and a 'Conclusion' to the results and discussions identified in all phases; to ensure the reader has a complete picture and understanding of the study as a whole. The chapter also covers the 'Significance of the study', 'Limitations of the study', and finally ends with the 'Recommendations' for further research, based on the overall findings of this study.

6.1 SUMMARY

The Bridges self-management programme (SMP) and its self-management intervention (SMI) workbook was identified to be beneficial and acceptable from the perspective of patients with stroke, caregivers and healthcare professionals; with positive effects reported on the participation of patients living with stroke in the UK (Jones et al., 2009, 2016; & McKenna et al., 2013, 2015). However, these SMIs are context specific, and to maintain the fidelity of the Bridges SMP, they cannot simply be transferred from one population to another (Jones, 2015); with any SMI needing to be culturally acceptable to the context in which it is being implemented (Cha et al., 2012). Due to the potential the Bridges stroke SMP and SMI workbook has to improve participation restrictions in patients living with stroke, Hale et al. (2014) conducted research whereby the original UK Bridges stroke SMI workbook was successfully adapted and contextualized for the stroke population in the New Zealand context. SMIs, due to their nature of improving one's self-efficacy and encouraging individuals to manage their own symptoms, treatment, and lifestyle changes (Lennon et al., 2011), are preferred in resource constraint environments, such as in South Africa; as they empower and allow for the individual to take ownership of their healthcare and rehabilitation, and therefore reduce the burden of care on the limited available community healthcare rehabilitation resources. It was therefore hypothesized by the researcher, based on the findings of

Jones et al. (2009, 2016), McKenna et al. (2013 & 2015), and Hale et al. (2014) that a stroke SMI workbook that has been adapted and contextualized for the resource-constrained and healthcare professional dependent South African context could have similar beneficial and positive effects in addressing participation restrictions experienced by patients living with stroke in the Western Cape, South Africa.

6.2.1 Objective 1 and 2

Objective one and two sought to explore the views of local healthcare professionals' (HCPs) and patients with stroke on the implementation of the original UK Bridges stroke SMI workbook for the South African context. Focus group discussions (FGDs) were held with these participants at two step-down rehabilitation facilities, Life Esidimeni Intermediate Care and Booth Memorial Hospital, in Mitchells Plain and Oranjezicht respectively. During the FGDs with the HCPs (Phase 1) and patients with stroke (Phase 2), 16 themes were identified from the participants' views of the original UK Bridges stroke SMI workbook that required consideration by the researcher for the adaptation and contextualization process for the production of the first draft South African Bridges stroke SMI workbook. These two objectives were successfully accomplished with the researcher gaining an understanding the relevant views held by the HCPs and patients with stroke.

6.2.2 Objective 3

Objective three aimed to explore the experiences of South African patients living with stroke for the purpose of inclusion in the adapted and contextualized South African Bridges stroke SMI Workbook. Using one-on-one interviews, five patients who were living with a stroke in the South African community provided their experiences to the researcher (Phase 3). Seven overarching themes were clearly identified as being integral to the journey of a South African patient with stroke; with all themes obtained relating well to the Bridges SMP and established sections of the original UK Bridges stroke SMI workbook, either directly in the workbook itself, or indirectly. The third objective was successfully achieved with the researcher including the five appropriate vignettes of South African patients with stroke in the draft South African Bridges stroke SMI workbook.

6.2.3 Objective 4

Objective four sought to identify aspects of the original UK Bridges stroke SMI workbook that required adaptation and contextualization for the South African stroke population. This adaptation and contextualization process was divided into three stages by the researcher. Stage one of the adaptation and contextualization process for the production of the first draft South African Bridges stroke SMI workbook involved inclusion of feedback received from Objectives 1, 2, and 3 as described above. The changes to the original UK Bridges stroke SMI workbook included: 1) moving of the 'Reflection' chapter from the front of the workbook to the back; 2) usage of five appropriate UK vignettes from the original workbook, and the addition of the five newly developed South African vignettes from Phase 3; 3) inclusion of South African contextually rich and relevant pictures; and 4) addition of a 'Stroke Education' chapter. There were several areas of the original UK Bridges stroke SMI workbook design that was proposed for change but required the intervention of the Bridges professional designer to sign off; and as such, are to be sent to the designer as recommendations for the final South African Bridges stroke SMI workbook version. These proposed changes include: hard front and back covers for the workbook, use of rainbow colour scheme throughout the workbook, and cut-out navigational tabs.

Stage two of the adaptation and contextualization process involved a peer-review, by an expert panel, of the newly developed first draft of the South African Bridges stroke SMI workbook. Feedback was received from the Bridges Organization director and from the New Zealand Bridges principle researcher, which highlighted valuable points that required careful consideration by the researcher for the production of the final draft of the South African Bridges stroke SMI workbook. Changes at this stage included: 1) the removal of images that permission was not granted for and ensuring compliance with intellectual property rights; 2) recognition of appropriate stakeholders in the workbook; 3) new high-quality images of the participants were captured for use in the workbook; 4) use of the word 'expert' was limited; and, 5) descriptors for the useful contacts section were added. There were several areas of the first draft South African Bridges stroke SMI workbook design that was proposed for change by the experts that could not be attended to by the researcher. The first being the production of a professional end-product; with the researcher planning to send the final draft

version of the South African Bridges stroke SMI workbook to the Bridges professional designer prior to implementation with the South African stroke population. Secondly, the addition of further vignettes to address the functional and ethnic diversity gap in the included vignettes, which is noted below as a limitation of the study for future correction should the South African Bridges stroke SMI workbook be feasible.

Stage three of the adaptation and contextualization process involved further consultation, through use of FGDs with local neurological healthcare professionals, to discuss their views of the contextual relevance and implementation of the final draft South African Bridges stroke SMI workbook for the local South African stroke population. Several changes were proposed for consideration, namely: 1) additional workbook guidance, over-and-above the introductory instructions, which was not observed by the researcher as it would be contrary to the intention of the workbook to promote self-management strategies in the users and would further exacerbate the HCP-patient dependency relationship; 2) content wording needed to be more aphasia-friendly, which the researcher took note of for recommendation to the Bridges professional designer for inclusion with the final version of the South African Bridges stroke SMI workbook; 3) limited ethnic and functional diversity in the content of the vignettes, which is noted below by the researcher as a limitation of this study for future correction should the South African Bridges stroke SMI workbook be feasible; finally, 4) the use of patient words verbatim in the workbook vignettes was argued for and identified by the researcher through literature to be the most suitable for this study for effective user engagement with the workbook content in the local context.

6.2 CONCLUSION

The researcher set out to question ‘What are the components of an adapted and contextualized South African Bridges stroke SMI workbook for patients living with stroke in the Western Cape, South Africa?’. In response to this question, the researcher found that a stroke self-management intervention needs to include vignettes that are contextually relevant. It is therefore important that the content, wording, and pictures of the vignettes are reflective of the local context. The self-management intervention should also include stroke-specific health education. Considering the above, the researcher developed the first ever South African Bridges stroke SMI workbook with these crucial components in mind.

6.3 SIGNIFICANCE OF THE STUDY

The preliminary findings of this study, and the development of the first contextually sound, culturally relevant South African Bridges stroke self-management intervention (SMI) workbook, has potentially far reaching benefits for the local stroke population, should the intervention be found to be feasible for local implementation in subsequent research studies. Firstly, the workbook provides a contextually relevant stroke resource, with an appropriate health education component, that local HCPs can access to augment their approach to encouraging self-management with their patients, allowing local patients with stroke to be able to relate to the local stories.

Secondly, the South African Bridges stroke SMI workbook could play a role in reducing participation restrictions of patients with stroke in the Western Cape, South Africa, through positively influencing their self-efficacy levels and encouraging these individuals to be more independent and actively involved in their community. Through use of the South African Bridges stroke SMI workbook, and implementation of the self-management concepts, a reduction in the overall burden of care on local communities is possible; as the individual is encouraged to be more independent and less reliant on those around for completion of activities of daily living and participation.

Furthermore, the South African Bridges stroke SMI workbook would be useful in a resource-constrained environment through the alleviation of the home- and community-based resources, including the under-resourced healthcare professionals; with users of the workbook being less dependent on healthcare professionals, and using available community resources more appropriately.

Finally, the significance of this study and the developed South African Bridges stroke SMI workbook ties in with the goal of Healthcare 2030, as described by the Western Cape Department of Health (WCDOH, 2014), by assisting to achieve 'a person-centred approach' to healthcare; and a strengthening of the Primary Health Care (PHC) service platform, so as to promote individual and community responsibility for the health and care of self and others. In this way, the South African Bridges stroke SMI workbook allows a good starting point for the introduction of a South African self-management programme (SMP) that could be responsible for a progressive change in our approach to healthcare that goes far beyond stroke intervention.

6.4 LIMITATIONS OF THE STUDY

The researcher does note several limitations to this research study. The first being the implementation of an 'Exploratory' research design, noted by Dudovskiy (2016) as having some disadvantages to its use. These disadvantages include that these types of studies can generate qualitative data that is subject to bias; and, may make use of modest sample sizes that do not accurately represent the target population, and as such cannot be generalized.

Secondly, as highlighted by one of the experts, the vignettes in the South African Bridges stroke SMI workbook need to address a more diverse population and individuals with varied levels of functioning. Greater diversity in function and ethnicity of the included vignettes would allow for a larger stroke population group in South Africa to relate and benefit from using the SMI workbook; and therefore, will require attention in future related studies.

The research setting also yielded responses from a specific group of healthcare professionals and patients which could have been different had the setting been expanded.

The adaptation and contextualization of the Bridges stroke SMI workbook was conducted using the English version. It is currently therefore only applicable to South African patients with stroke who are able to read and understand English.

6.5 RECOMMENDATIONS

The researcher notes several recommendations related to the content of the South African Bridges stroke SMI workbook, the clinical application thereof, and future research studies.

The first recommendation would be for a feasibility pilot study to be conducted in South Africa on patients living with stroke using the adapted and contextualised South African Bridges stroke SMI workbook developed in this study as a tool for the implementation of a SMI program.

The second recommendation would be for the translation of the South African Bridges stroke SMI workbook content into other official South African languages so as to negate the perceived language barrier and allow the tool to be relevant and applicable to more of the South African stroke population.

Thirdly, as it relates to the clinical application of the South African Bridges stroke SMI workbook; it is highly recommended that HCPs who aim to implement the workbook be trained appropriately so as to maintain the fidelity of the program and ensure appropriate and successful delivery of the content to its users.

Fourth, to negate the literacy barrier, it is recommended that the South African Bridges stroke SMI workbook content and concept be produced in a video format, which would allow for users who are either illiterate or unable to manage the physical workbook, the opportunity to engage with the content. The video content could also be produced to complement the workbook and allow for a more holistic approach to learning and engaging with users.

Finally, this study took place using sub-acute and chronic settings; for future research interest and to expand the findings of this study as it relates to diversity, information on the appropriateness of the Bridges stroke SMI workbook and concept in different settings (acute setting) would therefore be of interest. Further research should focus on evaluating the effectiveness of the adapted South African Bridges stroke SMI workbook through a feasibility study that could be a randomized control trial. A sample size that demonstrates sufficient power and includes patients with cognitive impairments should be considered. As mentioned above, the setting should accommodate a diverse sample with appropriate healthcare professionals such as social workers and psychologists. Although the evaluation will consist mainly of a quantitative approach, the inclusion of a qualitative aspect would be appropriate.

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ANNEXURE A



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INFORMATION SHEET FOR HCP PARTICIPANTS (Phase One)

Project Title: The Adaptation and Contextualisation of the Bridge's Stroke Self-Management Intervention for Patients Living with Stroke in the Western Cape, South Africa.

What is this study about?

This is a research project being conducted by Ryan Clive Groenewald, of the University of the Western Cape. We are inviting you to participate in this research project because you, as a neuro-rehabilitation healthcare professional, fulfil the requirements to make this study possible. The purpose of this research study is to identify if a Stroke Self-Management Intervention workbook, that has been adapted and contextualised to South Africa, would be feasible to implement. If found to be feasible, to also provide rehabilitation guidelines to healthcare professionals, in the use of a stroke self-management intervention workbook, so as to reduce participation restrictions experienced by patients with stroke living in the community.

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

You will be asked to take part in a focus group with other neuro-rehabilitation healthcare professionals and the researcher at your place of work – either at Life Esidimeni Intermediate Care (LEIC) and Booth Memorial Hospital. This focus group will be aimed at determining the appropriateness of the Bridges UK Stroke self-management intervention workbook layout, content and overall usability for use in the South African setting. You may also be asked to be a part of a Delphi-study, whereby you give you expert input into the final adapted and contextualised stroke self-management workbook.

Would my participation in this study be kept confidential?

The researcher will endeavour to keep your personal information confidential at all times. To help protect your confidentiality, whether included or excluded from the study, no information will be disclosed to any unauthorized parties. The use of password-protected computerized files, as well as identification coding on information gathered, will be used. Your name will not be included on the collected data. A code will be placed on the questionnaires and other collected data, through the use of an identification key. Only the researcher will be able to link your relevant information to your identity as only the researcher will have access to the identification key. If we write a report or article about this research study, your identity will be protected to the maximum extent possible.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning potential harm to you or others.

What are the risks of this research?

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

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the researcher learn more about the feasibility of a South African Bridges stroke self-management intervention workbook for use in patients with stroke in the community. We hope that, in the future, other people might benefit from this study through improved understanding of this subject. With the correct knowledge and research data, treatment regimes could be drawn up that focus rehabilitation in the correct area and in the correct manner, allowing for the stroke individual to obtain maximal functional outcomes and independence.

Do I have to be in this research and may I stop participating at any time?

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

What if I have questions?

This research is being conducted by Ryan Clive Groenewald, of the physiotherapy department, at the University of the Western Cape with the assistance of supervisor Professor Anthea Rhoda. If you have any questions about the research study itself, please contact Ryan Clive Groenewald at: Life Esidimeni Intermediate Care, 103 Highlands Drive, Mitchells Plain, Cape Town, South Africa. 021 370 9800 or by email at: ryan.groenewald@lifehealthcare.co.za.

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

Thesis supervisor: Professor Anthea Rhoda
arhoda@uwc.ac.za
University of the Western Cape
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Bellville 7535

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

Prof José Frantz
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This research has been approved by the University of the Western Cape's Senate Research Committee. (REFERENCE NUMBER: BM/16/3/20)



ANNEXURE B



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INFORMASIE BLAD VIR GESONDHEID PERSONEEL

Titel van navorsingsprojek: Ontwikkeling van 'n gemeenskap-gebaseerde programme om die beperkings ervaar deur beroerte pasiënte in stedelike, buitestedelike en landelike gemeenskappe in Suid-Afrika aan te spreek.

Waaroor gaan die studie?

Dit is 'n navorsingsprojek onder leiding van Prof Anthea Rhoda by die Universiteit van die Wes-Kaap. Ons nooi u om deel te neem in hierdie navorsingsprojek, want jy is 'n professionele gesondheidswerker wat betrokke is by die rehabilitasie van pasiënte met beroerte. Die doel van hierdie navorsingsprojek is om die re-integrasie van pasiënte met 'n beroerte te verbeter in hul gemeenskappe.

Wat sal van my verwag word om te doen as ek instem om deel te wees?

Jy sal gevra word om deel te neem in 'n fokusgroepbespreking of 'n Delphi studie. In die fokusgroepbespreking en Delphi bestudeer, sal jy gevra word om kommentaar te lewer op jou ervaring van die beperkings ervaar deur pasiënte met beroerte sowel as komponente wat ingesluit kan word in 'n programme wat deelname en re-integrasie van hierdie pasiënte kan fasiliteer.

Sal my deelname aan hierdie studie vertroulik hanteer word?

Jou inligting sal vertroulik hanteer word. Om jou vertroulikheid te help beskerm, sal geen name gebruik word tydens die insameling en ontleding van die data nie. Die klank opnames sal in 'n geslote kabinet wees en slegs die navorser sal toegang tot hierdie hê. As ons 'n verslag of artikel oor hierdie navorsingsprojek skryf, sal jou identiteit beskerm word tot die maksimum mate moontlik. Hierdie studie sal gebruik maak van fokusgroep besprekings die mate waarin jou identiteit vertroulik handhawing sal word is afhanklik van die deelnemers Fokusgroep.

Wat is die risiko's van hierdie navorsing?

Daar kan 'n paar risiko's wees wanneer jy aan hierdie navorsing deelneem. Alle menslike interaksies en praat oor self of ander voer 'n bedrag van risiko's. Ons sal nogtans sulke risiko's minimaliseer en sal vinnig optree om jou te help as jy enige ongerief tydens die proses van jou deelname aan hierdie studie ervaar. Waar nodig, sal 'n toepaslike verwysing gemaak word aan 'n geskikte professionele persoon vir verdere hulp of intervensie.

Wat is die voordele van hierdie navorsing?

Hierdie navorsing is nie ontwerp om jou persoonlik te help nie, maar die resultate kan die navorser help om meer te leer oor die beperkinge ervaar deur pasiënte met beroertes. Ons hoop dat in die toekoms, ander mense kan voordeel trek uit hierdie studie deur middel van verbeterde begrip van beperkinge ervaar deur 'n beroerte pasiënte en programme te implementeer wat hierdie beperkings kan adresseer.

Moet ek in hierdie navorsing, en kan ek ophou deelneem op enige tyd ?

U deelname aan hierdie navorsing is heeltemal vrywillig. Jy kan kies om glad nie deel te neem nie. As jy besluit om deel te neem in die navorsing, kan jy ophou om deel te neem op enige tyd. As jy besluit om nie deel te neem aan hierdie studie nie of as jy ophou om deel te neem, jy sal nie gestraf word of enige voordele waarop u andersins kwalifiseer verloor nie.

Wat as ek vrae het?

Hierdie navorsing word gedoen deur Prof Rhoda by die Universiteit van die Wes-Kaapland. As jy enige vrae oor die navorsing self, kontak:

Anthea Rhoda
Fisioterapie Departement,
Universiteit van die Wes-Kaap
Modderdamweg
Bellville, 7535
Telefoon: 021 9592542
E-pos: arhoda@uwc.ac.za



Indien u enige vrae oor hierdie studie en jou regte as 'n navorsings- deelnemer, of indien u enige probleme ervaar het met betrekking tot die studie en will dit aan meld kontak Dekaan van die Fakulteit Gemeenskap en Gesondheidswetenskappe:

Prof J. Frantz
chs-deansoffice@uwc.ac.za
Universiteit van die Wes-Kaap
Privaatsak X17
Bellville 7535
Telefoon: 021 959 2631

Hierdie navorsing is goedgekeur deur die Universiteit van die Wes-Kaap se Senaat Navorsing Komitee. (VERWYSINGSNOMMER: BM/16/3/20)

ANNEXURE C



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IPHEPHA LOLWAZI LWENGCAPHEPHE LEZEMPILO

Isihloko sofundo: Uphuhliso lwenqubo yasekuhlaleni ukubonisana nabathathi nxaxheba abathe bahlaselwa sistrowuki edolophini, emaphandleni nasezilalini eMzantsi Afrika

Lungantoni olufundo?

Olufundo luququzelelwe nguProfesa Anthea Rhoda kwiYunivesiti yase Ntshona Koloni. Siyakumema ukuba uthabathe inxaxheba kolufundo nanjengomnye wabantu abazingcaphephe kwezempilo ababandakanyeka ekubuyeiseleni isimo sesigulana esinesitrowuki kwimeko efanelekileyo. Injongo yesisifundo kukufumanisa ukuba abantu abanesitrowuki baphila njani ekuhlaleni.

Yintoni endizakuyibuzwa ukuba ndiyenze xa ndinokuthi ndithabathe inxaxheba?

Uzakucelwa uthabathe inxaxheba kwiqela elikhethekileyo okanye kwisifundo esizakubuza imibuzo engamelene nesigulana esinesitrowuki, uzakucelwa uchaze ngokoluvo lwakho indlela abantu abahlaselwe sisitrowuki abangakwaziyo ukuzibandakanya kuzo kwakunye nezinto ezinikuthi zifakelwe ukuncedisana nabo ukuze bakwazi ukuthabatha inxaxheba.

Ingaba ukuthabatha kwam inxaxheba kwesi sifundo kuzakukhuseleka?

Ulwazi lwakho luzakuhlala lukhuselekile. Ukukhusela ukufihlakala kwakho, akukho magama azakusetyenziswa ngexesha lokuqokelela nokuphicotha ulwazi olufunyenwe kuwe. Izinto ezishicilelweyo zizakutixelwa kwikhabhathi etixwayo eyakuthi ivulwe kumphicothi wezifundo kuphela. Ukuba sibhala ingxelo okanye iphepha eliyakufundwa ngowonke-wonke malunga nesi sifundo, ubunguwe buzakukhuseleka kwinqanaba eliphezulu. Esi sifundo sizakusebensisa iqela elikhethekileyo qaphela oku kukhuseleka kobunguwe kuzakuhlala kukhuselekile yaye kuxhomekeke kubathathi nxaxheba kwiqela elikhethekileyo kukhuseleka kwakho.

Buyintoni ubungozi besisifundo?

Zingakhona iingxaki ngokuthatha inxaxheba kwesi sifundo. Konke ukunxulumana nabantu nokuthetha ngawe okanye abanye bunobungozi obuthile. Sizakuzama ngandlela zonke ukunciphisa obobungozi yaye senze ngokukhawuleza ukukunceda ukuba uva ukungakhululeki, ukuphazimiseka ngengqondo okanye phakathi ngexesha uthatha inxaxheba kwesi sifundo. Apho kufanelekileyo, uyakuthunyelwa kwingcaphephe efanelekileyo ukukunceda okanye ukwenza into.

Yintoni endiyakuyizuza malunga nesisifundo?

Ungangafumani uncedo wena kodwa omnye umntu olandelayo angancedakala ngolwazi esiyakuthi siluqokelele apha, kwaye siyathemba kananjalo abantu bayakuncedakala kwixa eliziya ngexa yokuqonda ubunzima obukhoyo ngenxa yesisifundo.

Kunyazelekile ukuba ndithabathe inxaxheba kwesisifundo/ ndingakwazi ukuyeka uthabatha inxaxheba ukuba andifuni nokuba kunini?

Ukuthabatha inxaxheba kwesisifundo kungothanda kwakho akunyanzelekanga. Ungakhetha ukungathabathi nxaxheba konke- konke. Ukuba ukhethe ukuthabatha inxaxheba kwesisifundo unako ukuyeka nanini na. ukuba ufuna ukuyeka kwaye akukho ncedo ongazi ukulifumana ngenxa yoko.

Ukuba ndinemibuzo ndingenza njani?

Olufundo luququzelelwe nguProfesa Anthea Rhoda kwiYunivesiti yase Ntshona Koloni Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nkqubo wesisifundo kwezi ncukacha zilandelayo:

Prof Anthea Rhoda
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Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nkqubo wesisifundo kwezi ncukacha zilandelayo:

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ANNEXURE D



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INFORMATION SHEET FOR PATIENTS WITH STROKE (Phase 2)

Project Title: The Adaptation and Contextualisation of the Bridge's Stroke Self-Management Intervention for Patients Living with Stroke in the Western Cape, South Africa.

What is this study about?

This is a research project being conducted by Ryan Clive Groenewald, of the University of the Western Cape. We are inviting you to participate in this research project because you, as a patient suffering from a stroke, fulfil the requirements to make this study possible. The purpose of this research study is to identify if a Stroke Self-Management Intervention workbook, that has been adapted and contextualised to South Africa, would be feasible to implement. If found to be feasible, to also provide rehabilitation guidelines to healthcare professionals, in the use of a stroke self-management intervention workbook, so as to reduce participation restrictions experienced by patients with stroke living in the community.

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

You will be asked to take part in a focus group with other patients living with stroke, and the researcher, at the facility where you have been cared for - either Life Esidimeni Intermediate Care (LEIC) or Booth Memorial Hospital. This focus group will be aimed at determining the appropriateness of the Bridges UK Stroke self-management intervention workbook layout, content and overall usability. The focus group feedback will be voice recorded to ensure that all necessary information is obtained. A transcription of this focus group will be made and given back to you to check the accuracy of the information you provided.

Would my participation in this study be kept confidential?

The researcher will endeavour to keep your personal information confidential at all times. To help protect your confidentiality, whether included or excluded from the study, no information will be disclosed to any unauthorized parties. The use of password-protected computerized files, as well as identification coding on information gathered, will be used. Your name will not be included on the collected data. A code will be placed on the questionnaires and other collected data, through the use of an identification key. Only the researcher will be able to link your relevant information to your identity as only the researcher will have access to the identification key. If we write a report or article about this research study, your identity will be protected to the maximum extent possible.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning potential harm to you or others.

What are the risks of this research?

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

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the researcher learn more about the feasibility of a South African Bridges stroke self-management intervention workbook for use in patients with stroke in the community. We hope that, in the future, other people might benefit from this study through improved understanding of this subject. With the correct knowledge and research data, treatment regimes could be drawn up that focus rehabilitation in the correct area and in the correct manner, allowing for the stroke individual to obtain maximal functional outcomes and independence.

Do I have to be in this research and may I stop participating at any time?

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

What if I have questions?

This research is being conducted by Ryan Clive Groenewald, of the physiotherapy department, at the University of the Western Cape with the assistance of supervisor Professor Anthea Rhoda. If you have any questions about the research study itself, please contact Ryan Clive Groenewald at: Life Esidimeni Intermediate Care, 103 Highlands Drive, Mitchells Plain, Cape Town, South Africa. 021 370 9800 or by email at: ryan.groenewald@lifehealthcare.co.za.

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

Thesis supervisor: Professor Anthea Rhoda
arhoda@uwc.ac.za
University of the Western Cape
Private Bag X17
Bellville 7535

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

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INFORMASIE BLAD VIR PATIENTE MET BEROERTE

Titel van navorsingsprojek: Ontwikkeling van 'n gemeenskap-gebaseerde programme om die beperkings ervaar deur beroerte pasiënte in stedelike, buitestedelike en landelike gemeenskappe in Suid-Afrika aan te spreek.

Waaroor gaan die studie?

Dit is 'n navorsingsprojek onder leiding van Prof Anthea Rhoda by die Universiteit van die Wes-Kaap. Ons nooi u om deel te neem in hierdie navorsingsprojek, want jy is 'n persoon wat 'n beroerte ervaar het. Die doel van hierdie navorsingsprojek is om die re-integrasie van pasiënte met 'n beroerte te verbeter in hul gemeenskappe.

Wat sal van my verwag word om te doen as ek instem om deel te wees?

Jy sal gevra word om 'n vraelys te voltooi. In bykomend tot die voltooiing van die vraelys kan jy ook gevra word om deel te neem in 'n groep bespreking waar jou ervarings met re-integrasie sal bespreek word. Sekere beroerte pasiënte sal ook gevra word om deel te neem in die programme wat ontwikkel sal word en hulle sal gevra word om vraelyste te voltooi aan die begin en einde van die programme. Die vrae wat gevra sal word, sal hoofsaaklik betrek jou vermoë om sekere aktiwiteite soos terugkeer na werk of sosiaal te vekeer, nou dat jy 'n beroerte gehad. Ons ook jou balans en loop spoed toets. Jy sal ook gevra word om 'n band vir ongeveer 'n week te draa sodat ons die die aantal stappe wat jy neem kan monitor.

Sal my deelname aan hierdie studie vertroulik hanteer word?

Jou inligting sal vertroulik hanteer word. Om jou vertroulikheid te help beskerm, sal geen name gebruik word tydens die insameling en ontleding van die data nie. Die klank opnames sal in 'n geslote kabinet wees en slegs die navorser sal toegang tot hierdie hê. As ons 'n verslag of artikel oor hierdie navorsingsprojek skryf, sal jou identiteit beskerm word tot die maksimum mate moontlik. Hierdie studie sal gebruik maak van fokusgroep besprekings die mate waarin jou identiteit vertroulik handhawing sal word is afhanklik van die deelnemers Fokusgroep.

Wat is die risiko's van hierdie navorsing?

Daar kan 'n paar risiko's wees wanneer jy aan hierdie navorsing deelneem. Alle menslike interaksies en praat oor self of ander voer 'n bedrag van risiko's. Ons sal nogtans sulke risiko's minimaliseer en sal vinnig optree om jou te help as jy enige ongerief tydens die proses van jou deelname aan hierdie studie ervaar. Waar nodig, sal 'n toepaslike verwysing gemaak word aan 'n geskikte professionele persoon vir verdere hulp of intervensie.

Wat is die voordele van hierdie navorsing?

Hierdie navorsing is nie ontwerp om jou persoonlik te help nie, maar die resultate kan die navorser help om meer te leer oor die beperkinge ervaar deur pasiënte met beroertes . Ons hoop dat in die toekoms , ander mense kan voordeel trek uit hierdie studie deur middel van verbeterde begrip van beperkinge ervaar deur 'n beroerte pasiënte en programme te implementeer wat hierdie beperkings kan adresseer.

Moet ek in hierdie navorsing, en kan ek ophou deelneem op enige tyd?

U deelname aan hierdie navorsing is heeltemal vrywillig . Jy kan kies om glad nie deel te neem nie. As jy besluit om deel te neem in die navorsing , kan jy ophou om deel te neem op enige tyd. As jy besluit om nie deel te neem aan hierdie studie nie of as jy ophou om deel te neem, jy sal nie gestraf word of enige voordele waarop u andersins kwalifiseer verloor nie.

Wat as ek vrae het ?

Hierdie navorsing word gedoen deur Prof Rhoda by die Universiteit van die Wes-Kaapland. As jy enige vrae oor die navorsing self, kontak:

Anthea Rhoda
Fisioterapie Departement ,
Universiteit van die Wes-Kaap
Modderdamweg
Bellville, 7535
Telefoon: 021 9592542
E-pos: arhoda@uwc.ac.za



Indien u enige vrae oor hierdie studie en jou regte as 'n navorsings- deelnemer, of indien u enige probleme ervaar het met betrekking tot die studie aan te meld, kontak Dekaan van die Fakulteit Gemeenskap en Gesondheidswetenskappe:

Prof J. Frantz
chs-deansoffice@uwc.ac.za
Universiteit van die Wes-Kaap
Privaatsak X17
Bellville 7535
Telefoon: 021 959 2631

Hierdie navorsing is goedgekeur deur die Universiteit van die Wes-Kaap se Senaat Navorsing Komitee. (VERWYSINGSNOMMER: BM/16/3/20)

ANNEXURE F



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IPHEPHA LOLWAZI LEZIGULANA EZINESITROWUKI

Isihloko sofundo: Uphuhliso lwenqubo yasekuhlaleni ukubonisana nabathathi nxaxheba abathe bahlaselwa sistrowuki edolophini, emaphandleni nasezilalini eMzantsi Afrika.

Lungantoni olufundo?

Olufundo luququzelelwe nguProfesa Anthea Rhoda kwiYunivesiti yase Ntshona Koloni. Siyakumema ukuba uthabathe inxaxheba kolufundo nanjengomnye wabantu abathe bahlaselwa sistrowuki. Injongo yesisifundo kukufumanisa ukuba abantu abanesitrowuki baphila njani ekuhlaleni.

Yintoni elindeleke ukuba ndiyenze xa ndinokuthi ndithabathe inxaxheba?

Ulindeleke ukuba ugcalise uphendule imibuzo eyakuthi ibuzwe kuwe, kwananjalo usenokucelwa ukuba uthabathe inxaxheba kwakunye neqela labanye abantu kwigumbi elinye apho kuyokuthi ubunzima okanye uncedo enithe nalufumana ngexesha niphila ne strowuki kuxoxwe ngazo. Abanye babaguli bayakucelwa ukuba bathabathe inxaxheba kwinqubo eziyakuthi zenziwe apho kwananjalo bacelwe ukuba baphendule imibuzo ekuqaleni nasekupheleni kofundo. Imibuzo eyakuthi ibuzwe apho imalunga nendlela owenza ngayo umsebenzi okanye indlela ongayo xa udibene nabanye abantu njengoko uthe wahlaselwa sistrowuki. Ukongeza sizakujonga indlela oxhathisa ngayo nendlela okhawuleza ngayo ukuhamba. Uzakucelwa unxibe ibhanti kangangeveki elizakubala amanyawo/izitepu ozithathileyo.

Ingaba ukuthatha kwam inxaxheba kolufundo luyakuba yimfihlo?

Siyokwenza kangangoko ukugcina iinkcukacha zakho ziyimfihlo. (1) Igama. Ifani okanye amanani esazisi sakho asisayikuzibhala phantsi kumaphepha lawo sobe siwasebenzisa;(2) sizakupha inani okanye ikhowudi leyo siyakuthi siyibhale phantsi endaweni yegama lakho (3) inani okanye ikhowudi leyo yiyo esiyakuyisebenzisa xa sifuna uphinda sibuyele kuwe (4) Ndim kuphela oyokwazi ngelonani okanye ikhowudi. Ukuba kuyenza sibhale incazelo malunga nesisifundo, siyakuzama kangangoko ukugcina iinkcukacha zakho ziyimfihlo.

Buyintoni ubungozi besisifundo?

Zingakhona iingxaki ngokuthatha inxaxheba kwesi sifundo. Konke ukunxulumana nabantu nokuthetha ngawe okanye abanye bunobungozi obuthile. Sizakuzama ngandlela zonke ukunciphisa obobungozi yaye senze ngokukhawuleza ukukunceda ukuba uva ukungakhululeki, ukuphazamiseka ngengqondo okanye phakathi ngexesha

uthatha inxaxheba kwesi sifundo. Apho kufanelekileyo, uyakuthunyelwa kwingcaphephe efanelekileyo ukukunceda okanye ukwenza into.

Yintoni endiyakuyizuza malunga nesisifundo?

Ungangafumani uncedo wena kodwa omnye umntu olandelayo angancedakala ngolwazi esiyakuthi siluqokelele apha, kwaye siyathemba kananjalo abantu bayakuncedakala kwixa eliziya ngexa yokuqonda ubunzima obukhoyo ngenxa yesisifundo.

Kunyazelekile ukuba ndithabathe inxaxheba kwesisifundo/ ndingakwazi ukuyeka uthabatha inxaxheba ukuba andifuni nokuba kunini?

Ukuthabatha inxaxheba kwesisifundo kungothanda kwakho akunyanzelekanga. Ungakhetha ukungathabathi nxaxheba konke- konke. Ukuba ukhethe ukuthabatha inxaxheba kwesisifundo unako ukuyeka nanini na. ukuba ufuna ukuyeka kwaye akukho ncedo ongazi ukulifumana ngenxa yoko.

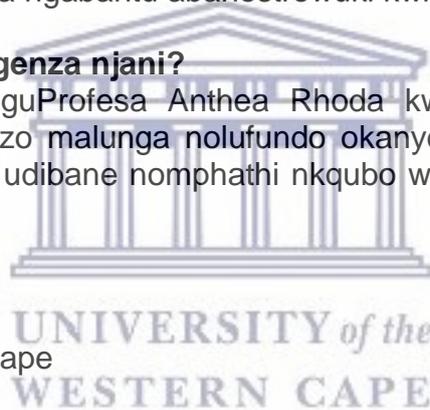
Ingaba lukhona uncedo endiyakulifumana ukuba kuyenzeka ndingancedakali sesisifundo?

Ewe, ukuba awuncedakalanga sesisifundo uyakuthunyelwa kwiziko labantu abaqeqeshelwe ukusebenza ngabantu abanestrowuki kwindawo ohlala kuyo.

Ukuba ndinemibuzo ndingenza njani?

Olufundo luququzelelwe nguProfesa Anthea Rhoda kwiYunivesiti yase Ntshona Koloni Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nkqubo wesisifundo kwezi ncukacha zilandelayo:

Prof Anthea Rhoda
Physiotherapy Department,
University of the Western Cape
Modderdam Road
Bellville, 7535
Telephone: 021 9592543
Email: arhoda@uwc.ac.za



Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nkqubo wesisifundo kwezi ncukacha zilandelayo:

Prof José Frantz
Dean of the Faculty of Community and Health Sciences
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This research has been approved by the University of the Western Cape's Senate Research Committee. (REFERENCE NUMBER: BM/16/3/20)

ANNEXURE G



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INFORMATION SHEET FOR PATIENTS WITH STROKE (Phase 3)

Project Title: The Adaptation and Contextualisation of the Bridge's Stroke Self-Management Intervention for Patients Living with Stroke in the Western Cape, South Africa.

What is this study about?

This is a research project being conducted by Ryan Clive Groenewald, of the University of the Western Cape. We are inviting you to participate in this research project because you, as a patient suffering from a stroke, fulfil the requirements to make this study possible. The purpose of this research study is to identify if a Stroke Self-Management Intervention workbook, that has been adapted and contextualised to South Africa, would be feasible to implement. If found to be feasible, to also provide rehabilitation guidelines to healthcare professionals, in the use of a stroke self-management intervention workbook, so as to reduce participation restrictions experienced by patients with stroke living in the community.

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

You will be asked to take part in a one-on-one semi-structured interview with the researcher, at your place of residence, for the purpose of identifying your experience of living with a stroke in the South African context. During these interviews, photographs may be taken of you while doing activities, as well as your surroundings. These photos will be taken for the purpose of inclusion in the workbook; whereby the patients with stroke who use the workbook will be more able to relate to the included stories.

Would my participation in this study be kept confidential?

Your involvement in this phase of the research is such that the information and photographs obtained from you would be for the benefit of other people to see. Therefore, you would agree that all information given and photographs taken, could be used in the creation of the workbook; as well as any subsequent presentations that may take place. The researcher will however, endeavour to keep your personal information confidential at all times. To help protect your confidentiality, whether included or excluded from the study, no information will be disclosed to any unauthorized parties. The use of password-protected computerized files, as well as identification coding on information gathered, will be used. Each participant will be given the option of using a pseudonym to protect their true identity should they wish. Your name will not be placed on the collected data. A code will be placed on the questionnaires and other collected data, through the use of an identification key. Only

the researcher will be able to link your relevant information to your identity as only the researcher will have access to the identification key. If we write a report or article about this research study, your identity will be protected to the maximum extent possible.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning potential harm to you or others.

What are the risks of this research?

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

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the researcher learn more about the feasibility of a South African Bridges stroke self-management intervention workbook for use in patients with stroke in the community. We hope that, in the future, other people might benefit from this study through improved understanding of this subject. With the correct knowledge and research data, treatment regimes could be drawn up that focus rehabilitation in the correct area and in the correct manner, allowing for the stroke individual to obtain maximal functional outcomes and independence.

Do I have to be in this research and may I stop participating at any time?

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

What if I have questions?

This research is being conducted by Ryan Clive Groenewald, of the physiotherapy department, at the University of the Western Cape with the assistance of supervisor Professor Anthea Rhoda. If you have any questions about the research study itself, please contact Ryan Clive Groenewald at: Life Esidimeni Intermediate Care, 103 Highlands Drive, Mitchells Plain, Cape Town, South Africa. 021 370 9800 or by email at: ryan.groenewald@lifehealthcare.co.za.

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

Thesis supervisor: Professor Anthea Rhoda
arhoda@uwc.ac.za
University of the Western Cape
Private Bag X17
Bellville 7535

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

Prof José Frantz
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
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Bellville 7535
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Email: chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Senate Research Committee. (REFERENCE NUMBER: BM/16/3/20).



ANNEXURE H



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ENGLISH INFORMED CONSENT FORM

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

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

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

Participant's name.....

Participant's signature.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Professor A. Rhoda
University of the Western Cape
Private Bag X17, Bellville 7535
Telephone: (021) 959 2542
Email: arhoda@uwc.ac.za

ANNEXURE I



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E-mail: ryangroen@rocketmail.co.za

TOESTEMMINGS FORM

Titel van navorsingsprojek: *Ontwikkeling van 'n gemeenskap-gebaseerde programme om die beperkings ervaar deur beroerte pasiënte in stedelike, buitestedelike en landelike gemeenskappe in Suid-Afrika aan te spreek.*

Die studie is aan my beskryf in 'n taal wat ek verstaan en ek stem vrylik en vrywillig in om deel te neem. My vrae oor die studie is beantwoord. Ek verstaan dat my identiteit nie bekend gemaak sal word nie en dat ek uit die studie kan ontrek sonder om 'n rede te gee eniger tyd en dit sal my nie negatief beïnvloed nie. Hierdie navorsingsprojek behels die maak van oudiobande. Die oudiobande sal gestoor word in 'n geslote kas by die Fisioterapie afdeling en slegs die navorser sal toegang tot dit het. Sodra die data ontleed is sal die bande sal vernietig word.

Ek stem saam dat my deelname aan hierdie studie op band opgeneem kan word.

Ek stem nie saam dat my deelname aan hierdie studie op band opgeneem kan word.

Deelnemer se naam

Deelnemer se handtekening

Datum

Hierdie navorsing word gedoen deur Prof Rhoda by die Universiteit van die Wes-Kaapland. As jy enige vrae oor die navorsing self, kontak:

Anthea Rhoda
Fisioterapie Departement,
Universiteit van die Wes-Kaap
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Bellville, 7535
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E-pos: arhoda@uwc.ac.za

ANNEXURE J



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IPHEPHA MVUME LOKUTHABATHA INXAXHEBA

Isihloko sesi sifundo: Uphuhliso lwenqubo yasekuhlaleni ukubonisana nabathathi nxaxheba abathe bahlaselwa sistrowuki edolophini, emaphandleni nasezilalini eMzantsi Afrika.

Olufundo lucacisiwe kum ngolwimi endiliqondayo kwaye ndizonyule ngokuthanda khona ukuze ndithathe inxaxheba. Imibuzo yam ebendinayo ngolufundo iphendulekile. Ndiyayiqonda into yokuba inkcukaca zam azisayi kuvezwa nokuba kubani, umzekelo, amagama wam kwakunye nenombholo yesazisi. Ndiyayiqonda into yokuba ndingayeka ukuthatha inxaxheba nangowuphi na umzuzu ngaphandle kokunika isizathu kwaye lonto ayiyi kuphazamisana nonyango lwam.

Kolufundo kuyakubakho ixesha lokuba kushicilelwe amacwecwe empendulo endiyakuthi ndiziphendule, kwaye loo macwecwe ayakugcinwa kwindawo ekhuselekileyo etixiweyo apho iyakuba ngulowo ebendibuza imibuzo onelungelo lokuvula apho.

- ___ Ndiyakuvumela ukushicilelwa kweempendulo zam xenikweni ndithatha inxaxheba kolufundo
- ___ Andikuvumeli ukushicilelwa kweempendulo zam xenikweni ndithatha inxaxheba kolufundo
- ___ Ndiyakunika imvume yokuhlola amaphepha wam asesibhedlele.
- ___ Andikuniki imvume yokuhlola amaphepha wam asesibhedlele.

Igama lomthathi nxaxheba.....

Umsayino womthathi nxaxheba.....

Umhla.....

Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nqubo wesisifundo kwezi ncukacha zilandelayo.

Nceda ukhumbule ukuba udibana nomphathi sifundo xa uthe wadibana nengxaki malunga nesisifundo kuphela.

Umququzeleli wesi sifundo: Prof. A. Rhoda
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ANNEXURE K



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FOCUS GROUP CONFIDENTIALITY BINDING FORM

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

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

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

Participant's name.....

Participant's signature.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Professor A. Rhoda
University of the Western Cape
Private Bag X17, Bellville 7535
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Email: arhoda@uwc.ac.za

ANNEXURE L



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IFOMU YEQELA EBOPHELELA IIMFIHLELO ZEQELA

IGAMA LOLUPHANDO LWENZIWA APHA: Uphuhliso lwenqubo yasekuhlaleni ukubonisana ngeziphazamisi ekuthatheni inxaxheba ezithi zifunyanwe ngabantu abathe bahlaselwa sistrowuki edolophini, emaphandleni nasezilalini eMzantsi Afrika

Olu phando lucaciswe kum ngolwimi endilugqondayo kwaye ndilaziyo. Imibuzo yam ngoluphando iphendulekile. Ndiyaqonda ukuba ukuzibandakanya kwam noluphando luzakuquka ntoni kwaye ndiyavuma ukuba ndiyafuna ukulwenza oluphando akukho mntu undinyazelisayo. Ndiyaqonda nokuba inkcukacha zam zizokugcinwa ziyimfihlo akukho mntu uzakuzixelwa okanye azinikwe. Ndiyaqonda ukuba ndingakwazi ukurhoxa koluphando ndingakhange ndinikeze sizathu kwaye ngaphandle loloyiko lokuba kukho into ezakwenzeka kum okanye kukho into endizophulukana nayo. Igama lomntu okwenziwa kuye uphando

Igama lomthathi nxaxheba.....

Umsayino womthathi nxaxheba.....

Umhla.....

Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nqubo wesisifundo kwezi ncukacha zilandelayo.

Nceda ukhumbule ukuba udibana nomphathi sifundo xa uthe wadibana nengxaki malunga nesisifundo kuphela.

Umququzeleli wesi sifundo: Prof. A. Rhoda

University of the Western Cape

Private Bag X17, Belville 7535

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ANNEXURE M

FOCUS GROUP DISCUSSION INTERVIEW GUIDE

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

Participant's name:

Participant's signature:

Date:

General Workbook Layout

1. How did you find the general layout of the workbook?
2. How practical is the workbook in its design and feel?

Workbook Content

3. What did you think of the overall content of the workbook?
4. How appropriate and applicable were the stories to you?
5. What stories stood out as being the most appropriate for you?
6. What stories stood out as being the most inappropriate for you?
7. How appropriate and applicable were the pictures to you?
8. What would you change in the workbook?

Workbook User-Friendliness

9. How did you find the overall user-friendliness of the workbook?
10. Were you able to navigate or find the section or chapter you were looking for?
11. Were you able to understand the flow of each section?

Implementation of this SMI in the South African Context

12. What are your views on the implementation of this SMI in our local context?

ANNEXURE N

INTERVIEW GUIDE (Phase 3)

Interview Number: _____

Interview Date: _____

The Bridges stroke workbook is being developed for people living with stroke in South Africa, would you consider being a 'story' and 'face' in this workbook? (Take the participant's photo if their answer is yes).

1. Tell me about yourself before the stroke, what do you like doing, what are you good at, can you give examples of things you have done in the past which have gone well, or you have overcome?
2. How did you feel when you first learnt that you had a stroke?
 - a. How did you respond at that time? What did you want to know? What might you have done differently?
 - b. What support did you have or would have liked to have?
 - c. What advice would you give others when they first learn they have a stroke?
3. Can you give some idea of how you manage day to day at the moment:
 - a. What are your main challenges?
 - b. What are some of the ways you get around things that you find challenging?
 - c. Can you tell us some of your tips and ideas that have worked for you?
4. Some people have said that life can have lots of twists and turns when they have one, or more, strokes - can you tell us a bit about what happened to you, what you have been through, and some of your ups and downs?
5. Some people have stressed the need to get away from thinking about their health condition all the time, how do you do that...what works for you?
6. What is a small thing that makes a big difference to your life with a stroke- how do you maintain being you?
7. Some people have said that finding ways of socialising can be challenging but is important to maintain being themselves and not their stroke. How do you maintain or build relationships with family and friends? How do you interact with people?
8. What do you think about the support you have living in Cape Town, are there groups, clubs or support that you think is unique to here?
9. Some people like to set small steps and targets to help them through each week or day- can you give us any examples of the targets or steps you have set which have worked or haven't worked?

10. Lots of people like to have a list of hopes and dreams, is there anything that's really important to you which might take a bit of time, but you want to try and do?
11. How do you cope when you have lots of visits from healthcare staff, it can get overwhelming for some people- do you have any tips or ideas for others going through the same?
12. What's the one thing you would like to tell someone in your position, such as: a bit of advice, idea, or tip?
13. Finally, thank you for your time and contribution, it will make a difference in other's lives.

