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THE DEVELOPMENT OF AN OUTCOME MEASURE TO ASSESS COMMUNITY REINTEGRATION AFTER STROKE FOR PATIENTS LIVING IN POOR SOCIOECONOMIC URBAN AND RURAL AREAS OF SOUTH AFRICA

Morake Elias Douglas Maleka

A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy.

Johannesburg, 2010

DECLARATION

I, Morake Elias Douglas Maleka declare that this thesis is my own unaided work. It is being submitted in fulfilment of the requirements for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. This thesis has not been submitted before for any degree or examination at any other university.

…… .....

Signature **Date**

PRESENTATIONS ARISING FROM THE THESIS

Public Health Association of Southern Africa congress May 2007 in Cape Town: Poster presentation. The development of an outcome measure to assess community reintegration following stroke for patients living in poor urban and rural socioeconomic areas of South Africa. Pilot study results.

World Confederation of Physical Therapy Africa Region Congress. Nigeria 2008: The development of an outcome measure to assess community reintegration following stroke for patients living in poor urban and rural socioeconomic areas of South Africa. Pilot study results. Platform Presentation.

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ABSTRACT

The prevalence of stroke is high in South Africa (Connor et al., 2007). However, in-hospital patient rehabilitation following stroke (Hale and Wallner., 1996; Rhoda and Henry., 2006; Mudzi., 2009) is limited, subsequently patients who have had a stroke have limited functional independence at discharge from hospital (Mamabolo et al., 2009). In addition community based rehabilitation services in South Africa are poorly developed and inadequate (Hale and Wallner., 1996; Rhoda and Henry., 2006; Mudzi., 2009). Therefore, patients are sent home without rehabilitation and they do not receive any once they are at home. Therefore, it is not known how well people reintegrate back into their communities following stroke. One reason for this dearth of knowledge is that there are no appropriate outcome measures to measure community reintegration of patients back into their communities. This is particularly so for patients living in poor rural and urban communities.

Outcome measures are an essential part of clinical quality management in rehabilitation, but need to take the context in which patients live into consideration. All outcome measures that assess community reintegration for patients with stroke, have been designed in developed countries, such as the United Kingdom, and are therefore not contextual for the type of patients seen in poor socioeconomic urban and rural communities in developing countries, such as South Africa.

The definition and components of community reintegration vary and differ depending on the setting and target population. Although there are similarities amongst the different outcome measures, differences occur in the definition and components of community reintegration based on contextual factors. Except for the Participation Scale, all the outcome measures reviewed were formulated in more affluent and developed countries. Some scales were considered by the author to be too long for use in a largely illiterate population where questionnaires are better when interviewer administered (the Craig Handicap Assessment and Reporting Technique, the Stroke Impact Scale, Participation Scale, the Stroke-Adapted Sickness Impact Scale Profile). Many scales were scored based on the visual analogue scale system and some use five or more points Likert scale, which does not lend itself easily to translation (the Reintegration to Normal Living Index, the London Handicap Scale, the Stroke Impact Scale, the Community Integration Measure, the Stroke Specific Quality of Life, and the Subjective Index of Physical and Social Outcome). Only six of these scales had been validated in a stroke population (the Reintegration to Normal Living Index, the London Handicap Scale, the Stroke Specific Quality of Life, the Subjective Index of Physical and Social Outcome, the Stroke Impact Scale and the Stroke-Adapted Sickness Impact Scale Profile).

Many scales were not specific to community reintegration and included very few items under the participatory domain (the Reintegration to Normal Living Index, the London Handicap Scale, the Stroke Specific Quality of Life, the Stroke Impact Scale, the Nottingham Health Profile, the EurolQol Quality of life Scale, the Soweto Stroke Questionnaire, the Medical Outcomes Study Short Form 36 and the Stroke-Adapted Sickness Impact Scale Profile). Based on this review of the tools developed to measure community reintegration, there did not appear to be a tool that would be appropriate to measure community reintegration following stroke in a black South African community; a measure that takes into account contextual, cultural, multi-lingual and illiteracy factors. As a result, the researcher set out to develop an outcome measure of community reintegration that would take into account all the environmental and personal factors of patients with a stroke living in poor socioeconomic rural and urban areas of South Africa.

With that in mind, the overall aim of the thesis was to develop, validate and test the reliability of an interview-administered outcome measure to assess community reintegration after stroke for patients living in poor socioeconomic rural and urban communities of South Africa. There are two parts to this thesis. The specific objectives of each of the studies are listed below:

Study 1

1. To conceptualise community reintegration from the perspective of individuals who have had a stroke and their caregivers in order to develop and construct the outcome measure.
2. To develop and construct the items of the outcome measure using the information gained from the interviews and a review of the literature.

Study 2

1. To validate the outcome measure using neurological and community based rehabilitation experts and patients who were interviewed in study 1.
2. To establish the reliability and factor structure of the outcome measure using factor analysis and internal consistency statistics.
3. To establish construct validity by comparing this newly developed outcome measure to another existing tool.

Study settings: A community setting in the Soweto primary health care clinics around Johannesburg-Gauteng province (urban) and primary health care clinics in Elim, Siloam-Limpopo Province (rural), South Africa.

The studies were carried out as follows: study 1 was qualitative in nature using semi-structured face to face interviews. Thirty two interviews were conducted with patients who had had a stroke and their caregivers, nineteen from the rural setting and thirteen from the urban setting. Interviews were recorded using an audiotape, transcribed word for word and the content analysed. Thematic content analysis was used to extract the statements concerning community reintegration, concepts were identified and grouped into themes. The document developed from this study was the new preliminary outcome measure used in study 2.

Study 2 was a combination of qualitative and quantitative studies conducted in order to validate the newly developed community reintegration outcome measure. The first validation phase used three Delphi technique rounds with local neurological and community based rehabilitation experts, a statistician, psychologist and two meetings of the nominal group technique with patients as well as caregivers from study 1 to establish face and content validity of this newly developed outcome measure. The second validation phase was a quantitative, cross sectional study which was two pronged. Firstly, homogeneity (internal consistency) of items contained in this newly developed outcome measure were assessed and secondly using factor analysis items were further reduced and the construct of the outcome measure was confirmed. One hundred and twelve patients and 104 patients from the urban and rural setting respectively were included in the study. The last validation phase was a quantitative, cross sectional study which compared this newly developed outcome measure, with another existing measure the Subjective Index of Physical and Social Outcome (SIPSO), to assess construct validity. Eighty patients were used for this purpose (40 for each setting).

From the analysis of the results of study 1, community reintegration was conceptualised from the perspective of patients as well as their caregivers. The conceptualisation phrased in a positive manner, incorporates the ability to move around in one's home and community, of not being isolated without having roles reversed and identity loss. The person should be able to work to sustain his/her life and not lose hope. Themes from the interviews gave rise to sixty seven items which were generated based on the interviews conducted and these items were categorized under 11 domains by the researcher. This document was used in study 2.

The results of study 2 phase one were: the 67 items that were generated in study 1 were reduced to 44 categorised under eight domains after three rounds of Delphi technique and two nominal group meetings with patients. Study 2 phase two, factor analysis and internal consistency statistics results: As a result of the new grouping of the items, the two settings ended with a different outcome measure each. In the rural setting 12 items were removed, leaving 34 items but only six items were removed from the urban setting outcome measure, leaving 40 items. The internal consistency of these two

newly formed outcome measures was very good (for both settings, the alpha coefficient was 0.95). The new outcome measure was named the Maleka Stroke Community Reintegration Measure (MSCRIM), the rural and urban setting versions. Study 2 phase three, compared the MSCRIM to SIPSO. High correlations (urban r = 0.88, p = 0.0001, 2-tailed and rural setting, r =.95, p = 0.000, 2-tailed) were found between the MSCRIM and the SIPSO. However, MSCRIM (both versions) contain items that are context specific to patients with a stroke living in poor socioeconomic urban and rural areas in South Africa.

The MSCRIM is therefore a valid and reliable measure to assess community reintegration following stroke for patients living in poor socioeconomic rural and urban communities of South Africa. This outcome measure is interview-administered to either patients who have had a stroke or their caregivers.

Key words: Stroke, development of outcome measures, community reintegration, poor socioeconomic, rural and urban areas

DEDICATION

I dedicate this work to:
My wife, Motlatsi, daughter, Regomoditswe, and son, Lesedi
to motivate them in the quest for academic excellence.

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LIST OF ABBREVIATIONS

ADL	- Activities of Daily Living
AIDS	- Acquired Immunodeficiency Syndrome
CHART	- Craig Handicap Assessment and Reporting Technique
CIQ	- Community Integration Questionnaire
EQ-5D	- EurolQol, Quality of life Scale
FA	- Factor Analysis
HIV	- Human Immunodeficiency Virus
LHS	- London Handicap Scale
MSCRIM	- Maleka Stroke Community Reintegration Measure
NHP	- Nottingham Health Profile
OM	- Outcome measure(s)
PCA	- Principal Component Analysis
PHC	- Primary Health Care
PS	- Participation Scale
QOL	- Quality of Life
SA	- Republic of South Africa
SA-SIP-30	- Stroke-Adapted Sickness Impact Profile
SF-36	- Medical Outcomes Study Short Form 36
SIPSO	- Subjective Index of Physical and Social Outcome
SIS	- Stroke Impact Scale
SSQ	- Soweto Stroke Questionnaire
SSQOL	- Stroke Specific Quality of Life
USA	- United States of America
UK	- United Kingdom
VAS	- Visual Analogue Scale
WHO	- World Health Organisation

CHAPTER 1

1. INTRODUCTION AND BACKGROUND

1.1 INTRODUCTION

The chapter will provide an overview of the whole study including the background, problem statement, the overall aim of the study, the objectives and the significance of the study. A summary of all studies conducted in this thesis will also be presented.

1.2 BACKGROUND

Stroke is one of the common major causes of long-term disability and among the top ten leading cause of disability worldwide (Feigin et al, 2003, Lopez 2006). This includes black people in South Africa (SA) (Disler et al., 1986). The prevalence of disabling stroke in SA is thought to be as high as it is in high income countries (Connor et al., 2007). Although stroke has been recognized for many years as an important cause of death and disability in high-income countries, its importance in low-income countries has only recently been emphasized. Cardiovascular diseases were thought to be diseases of a “western” style of life but more recently, they have become recognised as significant diseases in poor socioeconomic societies (Connor et al, 2004). However, little is known about the burden and nature of stroke in low-income countries, particularly in sub-Saharan Africa (Connor et al, 2004; Feigin et al, 2003).

Many patients with stroke remain limited in their participation in family and community activities, and have a poor quality of life post stroke, even after satisfactory levels of independence in daily living activities and mobility have been achieved following rehabilitation (Midwest Nursing Research Society, 2001). Similar results were reported in a study conducted amongst stroke survivors in Nigeria (Owolabi and Ogunniyi, 2009). In SA, the average length of stay in a tertiary hospital for patients with stroke is six days according to a study by Mudzi, (2009) and the contact period with physiotherapy is one day. Thus, patients may be discharged without being seen by a therapist to prepare the patient for discharge and community reintegration. Patients who have had a stroke have limited functional independence on discharge from hospital (Mamabolo et al., 2009). Hence, community reintegration is bound to be very difficult for this kind of patient.

This study was located in SA, in two different provinces, Gauteng and Limpopo provinces; chosen due to their diverse rural and urban composition (Statistic South Africa, 2001). Eighty

nine percent of Gauteng province could be considered urbanized however; it has low socioeconomic areas such as Soweto (South Western Township-black people settlement). Soweto is a low socioeconomic, high density, multilingual, multicultural urban community predominately comprising illiterate black people. Limpopo province on the other hand is more rural with only 11% of the province urbanised. The villages in this province, particularly around the Elim and Siloam areas although also described as poor/low socioeconomic, and comprised mainly of illiterate black residents, are different to Soweto in that they are low density, monolingual, monoculture rural communities (Statistic South Africa, 2001; Aitchison & Harley, 2004). According to Statistics South Africa (2001), townships (predominantly black people settlements on the outskirts of a town or city) and rural areas (previously disadvantaged areas or former homelands) are classified as poor/low socioeconomic areas.

Measuring community reintegration for the population living in areas described above is a challenge because of the lack of context specific and appropriate outcome measures. The problem is further compounded by the unavailability and inaccessibility of community based rehabilitation services in such areas, as these services are either non-existent or poorly developed particularly in the rural areas. *"Every person participating in a rehabilitation process hopes at the end-point to be happily situated, productively occupied, and effectively supported in the community"* (McColl et al, 2001: 429-432). Reintegration back into the community can arguably be the ultimate aim of rehabilitation (Maleka et al, 2008). However, measuring community reintegration is difficult as to date there has been no definitive definitions of community reintegration, as the construct is contextual to the environment that the patient lives in (von Koch et al., 1998; McColl et al, 2001). The focus of this thesis was the development of an outcome measure at the participation level of the International Classification of Functioning, Disability and Health (ICF), specifically to measure community reintegration after stroke. Specifically this thesis aimed to develop a stroke-specific and contextual outcome measure for patients with stroke living in poor socioeconomic urban and rural communities in South Africa.

The ICF (WHO, 2001) offers an appropriate framework in which outcome measures can be developed. The ICF define three levels of functioning namely: body structure and function (impairment), activity limitation and participation restriction. Despite its importance as a rehabilitation goal, participation is the least often measured of all rehabilitation outcomes (Mellick, 2000). Although decades of research and numerous instruments have been developed that are devoted to the assessment of impairments and activity limitations, equal efforts have not been directed towards the comprehensive assessment of participation (Mellick, 2000). The ICF provides an appropriate framework in which to develop a new

outcome measure. The focus of this thesis is the development of an outcome measure at the participation level of the ICF; specifically to measure community reintegration after stroke.

Participation according to the ICF is defined as involvement in life situations, whereas participation restriction is defined as problems individuals may experience in involvement in life situations (WHO, 2001). Community reintegration is an integral part of participation. In the past, the focus of rehabilitation has been primarily institution-based thus; less attention has been paid to community-based rehabilitation and community reintegration (Struthers, 2001; Maleka et al, 2008). As a result, there are few outcome measures that assess community reintegration. With an increasing awareness of the need for community-based rehabilitation (Maleka et al, 2008) the lack of outcome measures on the participatory side of the ICF framework spectrum becomes more evident particularly with long-term disability such as that experienced after stroke.

“An outcome measure (OM) is defined as a measurement tool e.g. an instrument; questionnaire or rating form used to document changes in one or more patient’s characteristics over time” (Cole et al, 1995: 5-6). The purposes of an outcome measure are to identify the patient’s ability at baseline, to document progress, measure change and finally to enhance clinical decision-making about the patient and the rehabilitation programme. The use of outcome measures in health care is to enable total clinical quality management (Cole et al, 1995). In order for therapists to provide holistic rehabilitation, outcome measures need to be appropriate at every level of the patient’s rehabilitation process, taking the patient’s context into consideration.

1.3 PROBLEM STATEMENT

The prevalence of stroke is high in SA (Connor et al., 2007), but in-hospital patient rehabilitation following stroke (Hale and Wallner., 1996; Rhoda and Henry., 2006; Mudzi., 2009) is limited, patients who have had a stroke thus have limited functional independence on discharge from hospital (Mamabolo et al., 2009). Community-based rehabilitation services in SA are poorly developed and inadequate (Hale and Wallner., 1996; Rhoda and Henry., 2006; Mudzi., 2009). Therefore, patients are sent home without receiving in-patient rehabilitation and they do not receive any rehabilitation at home. Consequently it is not clear how well people reintegrate back into their communities following stroke. Furthermore, we do not have an appropriate outcome measure (OM) to assess this entity (community reintegration) in the context of these patients.

Measuring community reintegration following stroke is problematic as the available outcome measures are not appropriate for the kinds of areas/locations and population seen in a developing country like SA. Commonly used outcome measures in stroke rehabilitation assess the impairments and activity limitations following stroke, and only a limited number of outcome measures are available to assess community reintegration (participation) post stroke (Duncan et al 2001). There are no stroke-specific outcome measures to assess community reintegration for people with stroke living in poor socioeconomic areas such as is found in South Africa. The available outcome measures of community reintegration were designed in developed countries such as Canada (Willer et al, 1994) and the United Kingdom (UK) (Trigg and Wood, 1999), where the context is different from the type of patients seen in developing countries such as SA, for patients with traumatic head injury (Willer et al, 1994).

Most of the existing outcome measures for community reintegration are self-administered; a problem for a population that is mostly illiterate. The majority of the outcome measures developed to date use a Visual Analogue Scale (VAS), which is a very abstract concept for people with low educational levels or Likert scales with four to ten responses to choose from and these responses are difficult to translate accurately for a local context and for patients to accurately respond to (Yazbek et al., 2009; Grebe**,** 2009; Akinpelu et al., 2007; Van Brackel et al., 2006b). An outcome measure specific to the South African context is required. Such an outcome measure should be interview-administered and should take into account the patients' context (von Koch et al., 1998).

1.4 OVERALL AIM OF THE STUDY

To develop, validate and test the reliability of an interview-administered outcome measure to assess community reintegration of patients following stroke in poor socio-economic urban and rural South African communities.

1.5 OBJECTIVES

Two individual studies were planned and executed to develop the above outcome measure to assess community reintegration following stroke. The specific objectives of each study are listed below:

Study 1

1. To conceptualise community reintegration from the perspectives of individuals who have had a stroke and their caregivers in order to develop the construct of the outcome measure.

2. To develop and construct the items of the outcome measure using the information gained from the interviews and from a review of the literature.

Study 2

1. To validate the outcome measure using neurological and community based rehabilitation experts and patients who were interviewed in study 1.
2. To establish the reliability and factor structure of the outcome measure using factor analysis and internal consistency statistics.
3. To establish construct validity by comparing this newly developed OM to another existing tool.

1.6 SIGNIFICANCE OF THE STUDY

The new outcome measure will potentially be used as part of clinical quality management to assess and monitor community reintegration following stroke. The new outcome measure could also potentially assist the health authorities, therapists/assistants, community rehabilitation workers, caregivers and patients with stroke in both a rural and urban community setting, to set realistic, appropriate, relevant rehabilitation goals and assist in the planning and development of appropriate, community-based rehabilitation intervention strategies to assist and facilitate the process of reintegration in the context of the patient's environment. The newly developed outcome measure may be useful to other developing countries such as those in Africa.

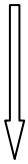
1.7 ETHICAL CONSIDERATIONS

Ethical clearance (see Appendix 1.1) for the whole study was obtained from the Human Research Ethics Committee (HREC) of the University of the Witwatersrand (M070816), and approval from respective provincial and local health authorities was also sought and obtained (see Appendix 1.2 and 1.3).

1.8 SUMMARY OF THE DEVELOPMENT OF THE OUTCOME MEASURE

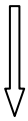
This section outlines the stages of the development of the outcome measure in a flow diagram. It explains how each stage was developed from the previous stage and outlines the content of each stage.

Development of an Outcome Measure:



Literature Review

Stage Outline: Global and local definition of community reintegration, used later in study 2 of this thesis.



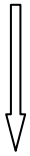
STUDY 1: **Qualitative Study**

Thirty two patients with stroke and caregivers in urban and rural areas of SA were interviewed in an attempt to understand and conceptualise community reintegration from their perspective.

Stage Outline:

- Conceptualisation of community reintegration and the effects of stroke on community reintegration.
- Development of the preliminary outcome measure according to emerging themes: item generation

STUDY 2: **Validation Studies**



Phase 1: **First item reduction process using experts' and patients' opinions**

Three rounds of the Delphi technique with neurological and community based rehabilitation experts and two nominal group technique meetings with patients/caregiver who participated in study 1.

Outline Stage:

- Assessment of face and content validity.
- Initial process of item reduction.
- Development of response scale (scoring system) by experts, in consultation with a statistician and psychologist.

⇩

Phase 2: Second item reduction process using factor analysis and internal consistency statistics

Stage Outline:

- Translation of initial OM to local languages (IsiZulu, South Sotho, XiTsonga and TshiVhenda) for data collection at this stage of the study.
- Intra-rater reliability was established on 12 patients in the urban setting and inter-rater reliability on 10 patients in the rural setting.
- OM administration to 112 patients in the urban areas and 104 in the rural areas in order to further reduce the items using factor analysis (FA).
- Reliability test to establish internal consistency of the items (initial).
- Regrouped items (from FA) to form new domains and finalise the scoring system.
- Second internal consistency test done.

⇩

Phase 3: Construct validity

Stage Outline:

- Comparing the new OM to the SIPSO.
- Eighty patients involved (40 from rural and 40 from urban settings).
- Development of the final outcome measure.

A general outline the whole thesis is presented below.

1.9 GENERAL OUTLINE OF THE THESIS

Chapter 1 **:** Introduction

Chapter 2 **:** Literature Review

Chapter 3 **:** Qualitative Study to Conceptualise Community Reintegration and the Development of the Preliminary Outcome Measure

Chapter 4 **:** Validation Studies, Phase One: Experts and patients

Chapter 5 **:** Phase Two: Factor Analysis and Internal Consistency Statistics

Chapter 6 **:** Phase Three: Comparison of the Newly Developed Outcome Measure (the MSCRIM) to the SIPSO

Chapter 7 **:** Discussion of the whole study

Chapter 8 **:** Conclusion and Recommendations

CHAPTER 2

2. LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents an overview and discussion of the literature related to this thesis. The chapter will start by discussing the prevalence and burden of stroke and the problems encountered with reintegration back into a community following stroke. The discussion will also include the International Classification of Functioning, Health and Disability as a framework followed by the definitions, domains and available outcome measures of community reintegration. The chapter will also review and discuss literature pertaining to the development of an OM and the challenges encountered with the use of OM's including the translation processes. The review will end by discussing the methodological approaches used in this study.

2.2 THE PREVALENCE, BURDEN OF STROKE AND REHABILITATION AFTER STROKE

Stroke, synonymously known as cerebrovascular accident (CVA) is defined according to the World Health Organisation (WHO) as "*rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death with no apparent cause other than vascular origin*" (WHO MONICA Project, 1988: 105-114).

There are very few systematic reviews of stroke mortality, prevalence and incidences in sub-Saharan Africa; only community based incidence studies will accurately reveal the burden of stroke (Connor et al. 2007). Community-based studies in African countries have shown that cerebrovascular diseases represent up to five to 10% of the causes of death, and that the prevalence of important risk factors for stroke (hypertension, diabetes and smoking) is increasing (van der Sande et al,. 2001; Walker et al., 2000; Khan and Tollman., 1999).

Until recently cardiovascular diseases were thought to be diseases of the rich but they are now emerging as prominent diseases in poor socioeconomic societies (Connor et al, 2004). However, little is known about the prevalence, burden and nature of stroke in low-income countries, particularly in sub-Saharan Africa (Connor et al, 2004; Feigin et al, 2003; Connor et al., 2007).

For many years stroke has been recognized as an important cause of death and disability in high-income countries however, its importance in low-income countries has only recently been

emphasized. The prevalence of disabling stroke in South Africa is thought to be as high as it is in high income countries (Connor et al., 2007). The prevalence of stroke is likely to increase in Sub-Saharan Africa in the future as the population ages and undergoes continuous epidemiological transitions, moving from a pattern of disease dominated by infection, perinatal illness, and other poverty related diseases to one dominated by non-communicable diseases (Connor et al., 2007; Connor et al., 2009).

The average length of stay (LOS) in hospital following a stroke in South Africa is short. The average LOS for a patient with stroke at a tertiary hospital in Soweto (Chris Hani Baragwanath) was reported to be 14 days in 2002 (Hale, 2002) and more recently this duration has been reduced to six days (Mudzi, 2009), with the average physiotherapy contacts for a patient with a stroke being one day (Mudzi, 2009). A study in the Western Cape province of South Africa, found that the majority of patients with stroke referred to community-based health centres were still in the acute stage post-stroke (Rhoda and Henry, 2006). It can therefore be deduced that a significant number of patients may be discharged early in the acute stage of stroke without receiving in-patient rehabilitation services. This sentiment is shared by Mamabolo et al., (2009), in their study to determine post discharge functional improvements in patients with stroke. They concluded by saying that patients who have had a stroke have limited functional abilities at discharge from hospital. Therefore, many patients are sent home inadequately rehabilitated and are as a result likely to be poorly reintegrated in their communities. The reintegration into community following stroke is a lengthy process. The adequate period for a person with stroke to be reintegrated back into the community following a disabling condition such as stroke is six months to one year (Stark et al. 2005).

In addition, as a result of poorly developed and inadequate community-based rehabilitation services in South Africa some patients may not receive any rehabilitation services at home or in their communities (Hale and Wallner, 1996; Garbusinski et al., 2005; Rhoda and Henry, 2006). Early discharge, very little in-patient rehabilitation, limited functional independence at discharge as well as a lack of community-based rehabilitation services may impact on community reintegration following a stroke as a result of limited ability to participate in family and community activities.

Community integration following a stroke is thus difficult as is discussed below.

2.3 COMMUNITY REINTEGRATION ISSUES FOLLOWING STROKE

Every person participating in the rehabilitation process hopes at the end-point to be happily situated, productively occupied and effectively supported in the community (McColl et al., 2001). However due to the lack of outcome measures to assess community reintegration following stroke within the context of an underprivileged (poor socioeconomic) society, it is difficult to quantify and qualify whether these hopes are achieved in the poor context of South Africa.

According to a systematic review by McKevitt et al., (2004) and a qualitative meta-synthesis by Salter et al.,(2008) there is a sizeable body of qualitative research that seeks to document the longer term impact of stroke, highlighting the needs that should be considered when planning and delivering longer term services including rehabilitation for people with stroke. The impact of stroke on survivors has repeatedly been documented as “the loss of...” in the qualitative literature, with the significance of reduced functional ability being explained in terms of loss of activities, abilities, personal characteristics and independence, emotional and social loss and a loss in or change in the individual ‘s own identity (McKevitt et al., 2004). Salter et al., (2008), shared the same observation in their study (a qualitative meta-synthesis) on the experience of living with stroke. Other studies have focused on the specific problems of “loss of the ability to drive” and the problems of “returning to the work force” particularly for younger people. Very little has been documented about return to school (education in general, including university) as it was thought that stroke is more likely to affect people with ages above school going age. All these issues affect the reintegration of a person who has had a stroke (McKevitt et al., 2004: 1499-1505).

The following factors are documented in the literature as the most common issues that affect a person’s reintegration following a stroke:

2.3.1 Loss of Ability to Perform Meaningful Activities

Stroke is widely recognized as being among the leading causes of long-term disability. Recovery from stroke is often defined in terms of physical and task-oriented improvement (Duncan & Lai, 1997). Doolittle (1992), in an ethnographic study of 13 people for up to six months following stroke found that although participants considered the ability to do more for themselves as important, the idea of recovery was seen to be a return to the life they lived before their stroke. However, this goal or recovery is often not achieved. Many people who have had a stroke live with physical, psychological and functional limitations that have an

impact on their abilities to perform activities of daily living, fulfil family and social roles, and thus return to the life they knew prior to the stroke (Dombovy et al., 1987).

Patients with stroke are not able to resume their previous activities (Parker et al., 1997) thus restricting their participation in daily living and social roles and limiting many aspects of their lives (Desrosiers et al., 2006a). Many people with stroke report lack or loss of meaningful activity (Desrosiers et al., 2006a) that have an impact on their daily activities and social roles. Meaningful activity in this instance refers to activities that people enjoy doing at home, work or in the community. In a study by Mayo et al., (2002), 39% of patients with stroke reported a limitation in functional activities while 54% reported limitation with higher-level functional activities of daily living such as dressing, bathing, housework and shopping and 65% reported restrictions in reintegration into community activities. Schmidt et al., (1986) reported that patients who have had a stroke generally function better in activities of daily living than they do in social activities and interactions.

Participation in meaningful daily activities for people who have had a stroke needs to be encouraged; a study by Desrosiers et al, (2006b) has shown that patients who participate in meaningful daily activities improve in function and that the improvement in function subsequently translates to other social activities in the community. The study further recommends that personal and environmental factors need to be investigated in order to prevent reduction and decline in social participation.

The loss of the ability to perform meaningful activities, leads to a perception that one's role or identity has been lost and the next section addresses this issue.

2.3.2 Loss of Personal Characteristics, Role or Identity and Change in Relationship(s) as a Result of a Stroke

The other area central to successful community reintegration of a person with stroke is the loss of their usual role within the family, community and society at large. This role is also described as a loss of personal identity (Ellis-Hill and Horn, 2000) or change in personal characteristics (McKevitt et al., 2004). One such role change is that the person may have to depend on others for his/her basic personal and social needs; this loss of independence (Hafsteinsdottir and Grypdonck, 1997), changes the position of the person within his/her family and community. Social roles can be altered when the patient can no longer work or dispense his/her responsibilities in a family and/or community. It is reported in a study by Grant, (1996) that

stroke survivors recognized distinct and individual functional, cognitive and emotional changes as a result of stroke and this affected the relationship they had with their family.

These changes frequently hinder performance of daily living activities and disrupt social activities they previously participated in with their family, because time is now spent assisting the survivor with his/her personal activities (Grant, 1996). Stroke survivors see this assistance as a shift in role or identity. A shift in social roles challenges relationships that are already stressed by the newly dependant status of the patient (Lynch et al., 2008). It is interesting to note that survivors often felt that their stroke placed severe pressure on family relationships, particularly when the stroke survivor had been the head of the household (brought in the majority of household income or held the most power and authority in family decision-making). In contrast caregivers are more likely to mention ways in which the stroke strengthens the patient's relationship with significant others (i.e. spouse and children) according to the study by Lynch et al., (2008) and brings a feeling of closeness to their spouse following a stroke (McKevitt et al., 2004).

2.3.3 **Loss of Mobility Independence and Ability to Drive**

Ambulation is an important predictor of community reintegration. According to Dunsky et al., (2008), walking disabilities are considered to be the most devastating disabilities post stroke. Lord and Rochester, (2005) and Buurke et al., (2008), define community ambulation as the ability to mobilise independently outside the home, including confidently negotiating uneven terrain, shopping centres, and other public venues. Less than 50% of stroke survivors progress to independent community ambulation (Buurke et al., 2008).

The loss of the ability to move around affects the independence of a person with stroke, thus leading to social isolation. Mayo et al., (2002), in a study to estimate the extent of activity and participation of individuals six months post stroke and their influence on health related quality of life in Montreal, Canada, reported that almost 50% of the community-dwelling stroke population lived with the sequelae of stroke such that, unless there was an able bodied caregiver at home, they needed some form of help.

The loss of independence was also reported by participants in a study by Hale et al., (1999) in Soweto, South Africa although most participants were independent in ADL; they expressed concern about their perceived loss of independence. Participants in this study felt that their walking speed had been tremendously reduced, resulting in them not being able to walk fast enough to cross the road or to be in a busy place like a shopping mall or town. Hale et al.

(1998a) found that 55% (over the age of 50 years) and 88% (below the age of 50 years) of participants were able to walk without assistance. Twenty four percent of both groups were able to walk the length of the road near their homes. The measure used to determine "handicap of gait" was the ability to catch a taxi, 46% of the older group and 69% of the younger were able to manage this activity. Ability to catch a taxi or bus in a country where most people are reliant on public transport is considered to be a measure of a person's ability to participate in the community.

In more affluent communities, driving a motor vehicle is essential to functional independence and community integration, as it enables access to work, shopping, health care and social activities (Griffen et al., 2009) and thus driving status has a considerable influence on community integration following stroke. A study by Griffen et al., (2009) showed that stroke survivors who had not resumed driving showed poorer community reintegration than did those who had resumed driving. Even though some stroke survivors used alternative public transport, the loss of independent driving was not fully compensated. In their study, cessation of driving appeared to more adversely affect males than females (Griffen et al., (2009).

It should also be pointed out that driving could also be part of a person's work requirements or occupation. Stroke may affect this skill negatively and alternate transport such as public and private transport or relying on friends and family often does not adequately meet the mobility needs of a person, especially of a person who drove before his/her stroke. Inability to drive as a work requirement affects the livelihood of a person and his family especially if the person is a breadwinner.

2.3.4 **Social Isolation**

Individuals with stroke disability often live a very isolated life thus leading to greater social isolation and withdrawal from community activities (Garbusinski et al., 2005). This social isolation is as a result of a number of factors such as loss of mobility and the lack of community based activities, for example, support groups in rural and urban areas (Boden-Albala et al., 2005). Social isolation has been defined as knowing fewer people well enough to visit them in their home or having visitors (Boden-Albala et al., 2005). This definition of social isolation/support represents a primary, informal network of relationships that incorporates family, friends or neighbours. Hence, relationships established prior to the first stroke may provide a mechanism for quicker reintroduction/reintegration into community organizations and resources. The majority of stroke survivors depend on others for their everyday activities.

Therefore, social relationships are critical to survival for patients after stroke and become of critical importance to their quality of life (QoL) (Lynch et al., 2008).

Socially isolated patients may be at particular risk for a poor outcome, in both function and QoL (Glass et al., 1993). Social support may be an important prognostic factor in recovery from stroke. Glass et al., (1993) in a study examining the impact of social support on outcome after a stroke, reported that high levels of social support are associated with faster and more extensive recovery of functional status. Garbusinski et al., (2005), further endorsed the concept of social support in a prospective observational study conducted in Gambia. In this study it was reported that most participants who were socially supported by a family member in the form of a spouse, sister, or children participated in family life and resumed activities of daily living such as caring for children, attending family ceremonies, social gatherings and other community related activities sooner than those who were not supported.

It has been suggested that to deal with the adverse effects of social isolation post stroke, increased funding for community organizations to promote leisure activities and other programmes in which people get together and share common interests may be needed to promote social support and ultimately reduce vascular morbidity and mortality (Boden-Albala et al., 2005).

2.3.5 **Loss of Hope**

Feelings of despair and helplessness are commonly expressed following a stroke (Pilkington, 1999). The concept of loss of hope can be characterized by expression of uncertain feelings of the future. The feeling of hopelessness is often due to the realisation that the newly acquired disability has to be coped with for the rest of the person's life (Pilkington, 1999) together with feelings of humiliation and loss of control (Hafsteinsdottir and Grypdonck, 1997; Western, 2007).

The recovery from stroke is equally stressful, usually necessitating significant coping efforts and strategies. Difficult life events such as stroke may encourage patients to re-examine aspects of their life, and the challenges associated with stroke can promote spiritual growth and development. Hope is important to recovery as it gives individuals the motivation and strength to achieve their goals (Western, 2007).Because of the life changing experience of stroke, spiritual practices may assist patients in finding meaning, hope and wholeness through the confidence they offer (Robinson-Smith., 2002). This notion is supported by a study by Lui and Mackenzie, (1999) on elderly Chinese patients following stroke. The researchers

discovered that spirituality was important at all stages of recovery following stroke. The participants believed that religious or spiritual belief gave them a sense of psychological comfort and hope for the future. The religious/spiritual rituals that they found to be beneficial included praying, reading religious books, burning incense and going to church.

Robinson-Smith (2000) in a study done in the USA also discovered that patients who expressed moderately high personal faith in God had a higher quality of life. It is important to note this psychological coping strategy of restoring hope, because knowing from where the patients draw hope may assist in encouraging the patient during rehabilitation; in turn this could potentially assist with community reintegration.

2.3.6 **Return to Work and School (Education in General)**

Another activity that is affected by stroke or affects community reintegration is people's ability to return to work. The inability to return to work affects the person's livelihood and existence. There are various definitions of work but the ones put forth by Vestling et al., (2003) and Malm et al., (1998)'s cover all aspects related to the definition of work in both formal and informal settings including schooling. Vestling et al., (2003: 127-131) defined work as a *"continuing occupation in the production of supplies and services for payment, meaning formal paid on a full-time or part-time-basis* and Malm et al., (1998: 433-440) defined work as *"any employment plus homemaker, volunteer activities, or student".*

Returning to work for people with stroke may contribute significantly to their life satisfaction, well being, self-worth and social identity, giving them an opportunity to maintain independence as far as physically possible with the income generated through employment (Wolfenden and Grace, 2009). Pressures such as financial hardship may influence return to work. Return to work may be seen as an indication of the recovery of a patient with stroke. Hale et al., (1999) reported that all the participants in their Soweto based study had financial problems. Some of the participants had been the sole sources of family income prior to the stroke and now found themselves and their families in dire straits (Hale et al., 1999). Garbusinski et al., (2005) found that less than half of the participants (n=143) in their study conducted in Gambia who were economically active before the stroke had one year later resumed a paid activity i.e. had returned to their paid jobs.

2.3.7 **Conclusion**

The problems of reintegrating a patient back into the community following stroke are many; some of these problems include loss of ability to perform meaningful tasks, loss of mobility,

loss of role and identity, social isolation and inability to return to work. The problems stated above seriously affect participation in life situations (participation restriction), thus leading to poor or no reintegration (Schmidt et al., 1986). All these issues are contextual and need to be taken into consideration when assessing community reintegration following a stroke, so that in the development of rehabilitation goals with patients and caregiver these issues may be addressed. Unfortunately, due to lack of and inappropriate OM's it is difficult to document these issues.

The next section discusses the ICF as this international classification was used as a framework for this study, because it provides a framework on which outcome measures could be developed.

2.4 INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH AS A FRAMEWORK FOR THIS STUDY

The International Classification of Functioning, Disability and Health, known as the ICF was developed by the World Health Organisation (WHO) for application in various aspects of health. The ICF belongs to the international classifications that provide a framework to code a wide range of information about health e.g. diagnosis, functioning and disability and it uses standardised common language permitting communication about health and health care across the world in various disciplines and sciences (WHO, 2001).

The overall aim of the ICF is to provide a unified and standardised language and framework for the description of health and related states. The domains/dimensions of ICF can be seen as health and health-related. These domains are described from the perspective of the body, the individual and society; namely body function and structure; activities and participation. Participation restriction occurs when an individual is unable to carry out his/her tasks or responsibilities due to a disease or illness. The restriction may not be due to body structure and function only, but may also be due to environmental and/or personal factors which are referred to as contextual factors in the ICF. Participation is a relatively recent concept that is not clearly understood or measured. This is one area of ICF that deserves much more attention as increasingly participation is considered as pivotal to the outcome of successful rehabilitation (Desrosiers, 2005).

Although decades of outcome research and numerous instruments or measurement tools have been developed that are devoted to the assessment of impairments and activity limitations,

equal efforts have not been directed towards the comprehensive assessment of participation, being the least often measured of all rehabilitation outcomes (Mellick, 2000). The WHO ICF provides a multi-dimensional framework for health and disability suited to the classification and development of a new outcome measure/instruments (Salter et al., 2005a). Outcomes may be measured at any of the ICF levels/domains. Participation is affected by environmental and personal factors (referred to as contextual factors within the ICF). It becomes more difficult to attribute outcomes to particular rehabilitation interventions as one moves away from body structure towards participation, since many variables other than the intervention might account for changes observed (Salter et al, 2005a). Community reintegration is an integral part of participation, because the concept takes into account the environmental and personal factors that cause participation restriction. (Salter et al., 2005a).

In the past, the focus of rehabilitation has been primarily institution-based, so less attention has been paid to the development and structuring of community-based rehabilitation services and reintegration back into the community (Hale and Wallner, 1996; Struthers, 2001; Maleka et al, 2008). As a result, there are few outcome measures that assess participation restriction or community reintegration. Due to early discharge, minimal or no rehabilitation in the hospitals (Maleka et al, 2008, Mudzi., 2009), limited functional independence at discharge from a hospital (Mamabolo et al., 2009) and underdeveloped community based rehabilitation (Hale and Wallner, 1996; Garbusinski et al., 2005; Rhoda and Henry, 2006) there is an increasing awareness of the need for the provision of community-based rehabilitation. However, the lack of outcome measures on the participatory dimension of the ICF framework spectrum becomes more evident particularly with long-term disability such as that experienced after stroke to qualify and quantify community reintegration.

The reintegration back into the community is the ultimate aim of rehabilitation (Maleka et al., 2008). The reintegration begins in the hospital and continues through to the patient's home. The patient's home context is different from that of a hospital. According to the online English Oxford dictionary, the word "context" refers "*to the surroundings, circumstances, personal factors (culture, level of education and spoken language), environment, background, or setting which determine, specify, or clarify the meaning of an event".* These issues/factors need to be taken into consideration because they may enhance community reintegration. Von Koch et al., (1998) in a study conducted in Sweden to explore the differences between a therapy session with a patient with stroke in two different settings, namely home versus hospital suggested that the context is a key component to be considered in the rehabilitation process of a patient with a stroke. However, to date there is an ongoing struggle with the definition and components of

community reintegration, because it is contextual (McColl et al., 2001; von Koch., 1998) to the environment that the patient lives in, and is also due to the lack of consensus regarding the construct of participation and its operationalisation (Desrosiers, 2005) and this is discussed below.

2.5 DEFINITIONS, COMPONENTS OF COMMUNITY REINTEGRATION AND AVAILABLE OUTCOME MEASURES

Reintegration to “normal” patterns of life is a subjective and contextual concept (Trigg et al., 1999, von Koch, 1998). The literature most commonly classifies reintegration into four domains, namely physical, functional, social and societal integration (Karlsudd, 2007). Various studies have attempted to identify and define these components of community integration.

Problems in defining reintegration and its components, has resulted in difficulties in developing appropriate OMs with which to assess this entity. The table below provides a summary of some commonly used outcome measures/scales that assess some aspects of community reintegration.

Table 2.1: Available Outcome Measures for some aspects of Community Reintegration

Name of the OM	Authors and origin	Target population	Domains measured	Ease of use/ training required	Comments/ Limitations
Reintegration to Normal Living Index **(RNLI)**	Wood-Dauphinee et al 1988, Canada	People with incapacitating disease or injury	11 items scale, covering participation level, use a VAS to score the persons response	Self, interviewer, proxy administered	Scoring system: VAS is abstract to most illiterate patients.
Craig Handicap Assessment and Reporting Technique **(CHART)**	Whiteneck 1992, United Kingdom (UK)	People with spinal cord injury, brain injury (**stroke**)	6 participation domains, valid and reliable	Self, interviewer, proxy administered	Generally long
Community Integration Questionnaire **(CIQ)**	Willer et al 1994, Canada	Persons with acquired brain injury	15 items scale, that covers home, social and productivity, valid	Self, interviewer, proxy administered	Q13, 14 and 15 are difficult to interpret.
London Handicap Scale **(LHS)**	Harwood et al 1994, United Kingdom	Adults with physical or neurological impairments	6 domains with 6 categories of answers, Valid, reliable and acceptable measure	Interview administered	Uses six point Likert scale, difficult to translate
Subjective Index of Physical and Social Outcome **(SIPSO)**	Trigg et al 2000, United Kingdom (UK)	patients with **stroke**	10 items measure, with scores ranging from 0-4, valid and reliable	Self report	Quick and inexpensive, Uses 5 point Likert scale.
Stroke Impact Scale- Version 3.0 **(SIS)**	Duncan et al 2001, United States of America (USA)	Patients with **stroke**	8 sections under each section are statements. Covers both impairments and participation level, reliable and valid	Interviewer administered	Too long, uses five point Likert scale. Calculation of the final score complicated
Community Integration Measure **(CIM)**	McColl 2001, Australia	People with brain injury	10 item checklist which covers participation level	Takes 5min to complete, could be self or interview administered	5 responses options-difficult to understand. Needs a certain level of literacy.
Participation Scale **(PS)**	Van Brackel et al 2006, Nepal, India and Brazil	Persons with leprosy or disability	18 item scale, based on ICF participation domains, valid	Reasonably easy to use, but require training. Interview administered.	Developed in developing countries. Need to constantly be comparing the patient to a peer, which is confusing.
Stroke-Specific Quality of Life (**SS-QOL)**	Williams et al. 1999, United States of America (USA)	Persons with **stroke**	12 domains and 49 items, mostly on participation level of ICF	Need training to use, interviewer administered.	5 point Likert scale

These outcome measures are discussed below in detail, including the definitions and components of community reintegration. Pertinent to this discussion is the critique of the outcome measure's validity for use in South Africa.

None of the reviewed outcome measures was found to be suitable for use to measure reintegration in a black South African context. Some of the factors considered that negated use in this context were (1) that many black South Africans are from a poor background, (2) many are illiterate, (3) a host of different languages are spoken, (4) there are a number of different cultural beliefs and practices, (5) people live in different circumstance from hutted villages, tin shacks to small houses with outside toilets (6) in many of the areas where black South African people live most of the roads are not tarred and (7) many people live far from the main road, where public transport is available. (8) The scales reviewed would have to be translated which in itself leads to a whole host of problems.

Below is a discussion of some of the reviewed outcome measures that assess parts of community reintegration and their limitations for use for a black South African population.

2.5.1 **Reintegration to Normal Living Index (RNLI)**

Wood-Dauphinee et al., (1988) defined integration as *"the organization of organic, psychological, and social traits and tendencies of an individual into a harmonious whole".* Therefore reintegration to normal living could mean "*the reorganization of physical, psychological and social characteristics so that the individual can resume well-adjusted living after an incapacitating illness or trauma like stroke"* (Wood-Dauphinee et al., 1988: 583-590). Wood-Dauphinee et al., (1988) used this definition in a qualitative study to develop an outcome measure for integration, the Reintegration to Normal Living Index (RNLI). Participants (n=109) in this study simplified the definition by suggesting that reintegration means "the ability to function, to do what one wants to do, or feels one has to do, not that one must be free of symptoms or even disability". (Wood-Dauphinee et al., 1988: 583-590)

The purpose of the RNLI is to assess the global functional status of patients who require long-term rehabilitation, including those with stroke. The information to determine the components of the Index were collected through interviews with professionals, patients and caregivers. The results of this study suggested that the following domains are related to reintegration to normal living, namely:

- Indoor activities, referring to the ability to move around one's dwellings/home as the patient feels necessary.

- Community refers to being able to move around one's community, as one feels necessary.
- Distant mobility refers to being able to take distant trips out of town as necessary.
- Self-care, refers to one being able to take care of one's self care needs e.g. bathing, feeding, toileting, bathing.
- Daily activity, in this instance refers to spending one's days occupied with work activity that is necessary or important to one.
- Recreational and social activities, refers to the ability to participate in recreational and social activities like hobbies, crafts, sports, reading, watching television, playing games on the computer and social activity with family and friends.
- General coping skills, refers to be able to deal with life events as they happen.
- Family roles, ability to assume a role in the family which meets one's needs and those of other family members.
- Personal relationships, refers to how comfortable one is with personal relationships.
- Presentation of self to others refers to how comfortable one is with self when one is in the company of others.

To score 11 items on this scale, recipients have to mark the degree of integration on a 10 cm visual analogue scale (VAS), the longer the distance of the mark from the anchor point at zero, the greater the perceived level of integration. The total score is the sum of all 11 items. The adjusted score is the total score divided by 110 multiplied by 100%. The RNLI has adequate inter rater reliability ($r = 0.62$; $p = 0.00$) and high internal consistency (Cronbach alpha= 0.90). Due to the scale being developed from participants with stroke perceptions, the content validity is considered good, but both construct and criterion validity require further attention (Wood-Dauphinee et al., 1988). RNLI was validated on adults with mobility limitations in the community by Stark et al., (2005) and considered by the authors to be a valid and reliable tool.

The limitation with regards to the use of RNLI in the South African context is that it is not a stroke specific measure and the scoring system uses a VAS which is thought to be a very abstract concept (requires abstract thinking ability) and is difficult to understand by patients who are illiterate such as those found in areas like Soweto, South Africa (Yazbek et al., 2009). In a South African study by Yazbek et al, (2009) to validate the use of pain rating scales including the VAS in Setswana speaking subjects, the authors concluded that subjects were confused and did not understand how to use the VAS. This the authors attribute to poor levels of education of the subjects. Teutsch, (2003) states that low functional health literacy may limit a patient's ability to comprehend, retain, recall and act on written health care measures (scales or questionnaires) with both literacy and numerical content.

2.5.2 **Craig Handicap Assessment and Reporting Technique (CHART)**

The CHART was developed by Whiteneck et al., (1992), to provide a simple, objective measure of the degree to which impairments and disabilities result in handicap (using the nomenclature at the time) (Mellick, 2000). It was initially developed for use with persons with spinal cord injury; however, the revised CHART (Mellick, 2000) has since been found to be an appropriate measure of handicap that can be used with individuals having a range of physical or cognitive impairments, including those caused by stroke. The instrument was designed to be administered by interview, either in person or by telephone and takes approximately 15 minutes to administer. It is also possible to use the instrument as a mailed or self-administered questionnaire.

The scale has five of the WHO dimension (domains) of handicap and comprises 32 questions. The dimensions are as follows:

- Physical independence: ability to sustain a customarily effective independent existence.
- Mobility: ability to move about effectively in his/her surroundings.
- Occupation: ability to occupy time in the manner customary to that person's sex, age and culture
- Social integration: ability to participate in and maintain customary social relationships
- Economic Self-Sufficiency: ability to sustain customary socio-economic activity and independence (Mellick, 2000).

Each of the domains or subscales of the CHART are scored out of a maximum score of 100 points, which is considered the level of performance typical of the average non-disabled person. High subscale scores indicate less handicap, or higher social and community participation (Mellick, 2000). Tozato et al., (2005), tested the validity of the CHART on Japanese individuals with spinal cord injuries and they concluded that the CHART was useful as a measure of disability for Japanese individuals with spinal cord injury.

A limitation of the scale for this study is that its validity and reliability for use with people with stroke has not yet been investigated. Furthermore, the scale was designed to be interviewer administered either face to face or by telephone; the latter is a major problem for most of the patients living in poor rural and urban socioeconomic areas such as those found in South Africa as the majority of people do not have landline telephones. Those who have mobile telephones have problems with limited network coverage.

2.5.3 **London Handicap Scale (LHS)**

The London Handicap Scale (LHS) was developed by Harwood et al., (1994), to measure the disadvantage experienced as a result of ill health (Jenkinson et al., 2000). It was developed for adults with physical and neurological impairments. Measures such as the LHS have great potential in the measurement of outcomes both in research settings and in the evaluation of clinical services for the purpose of audit and clinical governance (Jenkinson et al., 2000), as they measure participation in its entirety (though they still use the old nomenclature). The LHS has six dimensions (domains) of the international classification of impairment, disability and handicap (ICIDH) (the predecessor to the ICF) which are similar to the CHART except for the orientation domain in LHS, namely:

- Mobility
- Orientation refers to awareness of one's surroundings (world) and being able to find one's way around it.
- Occupation
- Physical independence
- Social integration
- Economic self sufficiency

The scoring system is a six point Likert scale ranging from none to extreme. The LHS uses weighted scales to derive a single handicap measure between 0 (extreme disadvantage) to 100 (no disadvantage) from the response to six questions. The LHS appear to be a valid, reliable and acceptable measure (Harwood et al., 1994; Harwood and Ebrahim., 1995). The correlation between the LHS and other measures is very high ($r = 0.90$; $p = 0.009$). However, the major disadvantage in using this measure is that the LHS uses a six point complicated Likert scale; this has been shown to be difficult to accurately translate into the context of the local South African languages for patients to respond to (Yazbek et al., 2009; Grebe, 2009) and thus makes it difficult for patients with low educational backgrounds such as the patients in Soweto and Limpopo province to understand or respond appropriately.

2.5.4 **Community Integration Questionnaire (CIQ)**

Willer et al, (1994) in their Community Integration Questionnaire (CIQ) identified only three factors constituting community integration for persons with head injury. These factors were identified by a group of experts interested in community integration for persons who have experienced traumatic brain injury. The experts met to establish consensus on what characterises an individual experience in the community. The group agreed on the following factors:

- Home, this refers to the person's ability to do household chores and care for self and children.
- Social, referring to the ability to be able to do shopping, visit relatives, friends and undertake leisure activities, and
- Productivity, which refers to the ability of a person to work and do voluntary jobs (Brain Injury Resource Foundation. 2004).

The purpose of this self-report questionnaire is to assess social role limitation and community interactions. The scale comprises 15 items related to home, social and productive activities. The scoring system is very item specific for an example items 1 to 6 are scored on a three point Likert scale and other items are scored on a dichotomous scale of yes or no. The CIQ score comes from the summation of the individual item scores and can range from 0 (poor integration) to 29 (high integration). Question 13, 14 and 15 are combined to form one item. The score for this question is chosen from variable patient responses. Scoring this question is very difficult as some of the responses may not be applicable to the patients. It is a valid tool to assess community reintegration for patients with traumatic head injury (Willer et al., 1994, Corrigan and Deming, 1995) but its use and validity to assess community reintegration following stroke still needs to be assessed. CIQ was developed for patients with traumatic head injury; the author acknowledges that its use in stroke outcome still needs to be assessed.

2.5.5 **Stroke Specific Quality of Life (SS-QOL)**

The SS-QOL scale is a patient-centred outcome measure intended to provide a quality of life assessment specific to survivors of stroke (William et al., 1999). It is a mail administered, self report scale containing 49 items within 12 domains namely:

- Energy in this scale refers to conservation of energy and the presence or lack thereof when performing activities of daily living.
- Family roles refer to family responsibility tasks, e.g. shopping, paying bills, banking and also how the person's physical health interferes with family life.
- Language this refers to general communication, .i.e. receptive and expressive language.
- Mobility in this instance is associated with the ability to maintain one's balance in all positions when moving around including with the use of a walking aid.
- Mood refers to the feeling of hopefulness, confidence and the feeling of intimacy as well as hunger.
- Change in personality following stroke.
- Self care refers to the ability to take care of one's personal needs, e.g. bathing, feeding, toileting.

- Social roles refer to fulfilment of social role and activities including leisure, recreation as well as self enjoyment activities.
- Thinking items in this domain include emotional status and the ability to remember things and events.
- Upper extremity function, the use thereof in performing activities of daily living.
- Vision, being able to see.
- Productivity/work items in this domain include both formal and informal jobs and tasks

Each item is rated on a 5-point Likert scale on one of three keyed response sets (Williams et al., 1999). Higher scores indicate better function. All domains of the SS-QOL have demonstrated excellent internal reliability (Cronbach alpha value = 0.73) (William et al., 1999; Salter et al., 2008). Muus et al., (2007) validated the Danish version of the SS-QOL and reported it to be a reliable (test-retest r = 0.65 - 0.99) and valid (Cronbach alpha = 0.81 - 0.94) instrument for measuring self-report QOL among people with mild to moderate stroke.

The SSQOL is very similar to SIS, in that it includes items that mostly assess impairments and activity limitation, with very few items in the participation domain. It is a mail administered, self report scale, which would be a problem for illiterate people living in poor urban or rural areas. The limitation with mail administered questionnaires for patients in this study is that most patients do not have street addresses, nor post boxes to receive letters. Secondly, the limitation with self reports is the inability of most patients to read and write; therefore, most patients would require assistance with completing the questionnaire (Grebe, 2009). The other limitation of this scale is that SSQOL is a new scale and not well studied though it has been tested among patients with severe stroke (Salter et al., 2005b) and found to be a useful scale to assess quality of life among stroke survivors.

2.5.6 **Subjective Index of Physical and Social Outcome (SIPSO)**

The Subjective Index of Physical and Social Outcome (SIPSO) is a 10 item self-completed questionnaire that measures social/community reintegration following stroke (Trigg and Wood, 1999) and was developed in 1999 in the UK. The SIPSO has three components of community reintegration namely:

- Activities
  - Every day activities are those that a person undertakes on a regular basis and reflects the person's ability to take care of themselves and overcome problems as they arise.
  - Leisure activities can be divided into two distinct categories within namely the home and those outside the home.

- Interaction which refers to relationships and communication within the home and outside the home

- Environment
  - Physical refers to the fact that their stroke has forced the person to reassess their living arrangement in terms of either the accommodation or the area in which they live.
  - Financial refers to changes in the financial status post stroke (Trigg and Wood, 1999).

The purpose of this outcome measure is to assess social/community integration following stroke. In the final draft of the outcome measure, the environmental factors were omitted as they failed to fulfil the criteria necessary for inclusion due to very low rotated factor loadings on factor analysis. The SIPSO has 10 items, with a five point Likert response scale. Kersten et al., (2004) reported it to have very good internal consistency (Cronbach alpha = 0.91). The test-retest reliability (ICC coefficient = 0.96) as well as construct validity (Spearman Ranked Correlation Coefficient = -0.09).

The limitations of the use of this tool in a SA situation are: firstly, it is a self-completed questionnaire that was developed in a developed country (UK), a problem to most illiterate people. It uses a 5 point Likert scale which is abstract to most illiterate patients and difficult to translate to local languages (Grebe, 2009). The SIPSO includes most items which assess community reintegration but in the development of the tool, the environmental items were removed from the scale. Environmental factors form part of participation according to the ICF so this is a notable omission.

2.5.7 **Stroke Impact Scale (SIS)**

The primary goal for the development of the SIS was to create a self-report instrument that would measure the full spectrum of stroke related outcomes, from the impairments to the handicap level, based on the ICIDH model and to be interviewer administered. The measure was also intended to specifically incorporate the quality of life goals of the recovering person with stroke and his/her caregiver (Duncan et al., 2001).

The domains were generated based on the ICIDH and are as follows: eight impairments, six disability and one handicap domain. The eight impairment domains included the following components: motor, oral-motor function, sensory, vision, memory and thinking, affect, emotion and language. The disability domain included the following aspects: self care, IADL, communication, basic mobility, community mobility and upper extremity function. The handicap

domain included the following items: work or volunteering activities, social, recreation, leisure and spiritual activities, family role functions, control of life and ability to help others.

The SIS uses a 5 point Likert response scale, rated on the difficulty of the item rather than on the degree of dependence. The time reference point is one week for impairments, two weeks for disability and four weeks for role function. The reason for the choice of these reference points was based on the fact that stroke-related impairments are detectable to patients on a daily basis whereas self assessment of disability and handicap depend on the opportunity to perform or participate in activities, so longer periods are necessary. The final score is calculated as 100 x [(actual score-lowest possible score)]/ possible range (Duncan et al., 2001). The SIS was found to be reliable (Cronbach alpha ranged from 0.83 to 0.90), valid (p values ranged from 0.02 to 0.0001) and sensitive to change in people with moderate strokes (Duncan et al. 1999). Each of the eight domains approached the standard of 0.9 alpha coefficients meaning the items contained in the scale are homogenous. The Intra Class Coefficient (ICC) for the test-retest reliability of the SIS domains ranged from 0.70-0.92 except for the emotional domain (ICC= 0.57) Duncan et al., (1999). Rasch analysis further established the validity of the SIS (Duncan et al., 2003).

The major limitation of the SIS for use as a measure of community-reintegration is that it contains domains and items across the ICF continuum i.e. from impairment to participation and thus there is only one domain that assesses participation. Additionally the calculation of the final score is complicated. In its favour the SIS is the only scale reviewed that has included intimacy as an item. However, the discussion of intimacy has been a problem in developing countries especially in rural areas as it is culturally inappropriate to discuss this matter especially between old and young people (Lo et al, 2001).

2.5.8 **Community Integration Measure (CIM)**

The Community Integration Measure (CIM) McColl et al., (2001) is a questionnaire developed for use with people with traumatic brain injury and comprises four factors constituting community reintegration:

- Assimilation refers to conformity, orientation and acceptance,
- Social support refers to both close and diffuse relationships;
- Occupation in this instance refers to leisure and productivity
- Independent living refers to personal independence, satisfaction with living arrangement.

The CIM has 10 items, each item has five response options (ranging from five = always agree to one = always disagree). Scores for each item are summed up, giving a total score between 10 and 50. A total of 50 represents a high level of community integration. The CIM is reported to be a valid and reliable (r = 0.88 and internal consistency = 0.70) outcome measure (McColl et al., 2001).

CIM is a very short scale but it excludes the item “productivity of work”, which is vital to the community reintegration of a patient who has had a stroke. Secondly, it focuses primarily on assessing impairments and activity limitation as opposed to participation. The major limitation of the use of this scale in a SA context is its five point Likert scale; which as previously described is difficult to translate to the local South African languages. Thirdly the scale was developed for patients with traumatic brain injury and although the items are very generic, it is not specific to stroke. Lastly, the tool was developed as a self-administered tool, and although it could be interview administered, it does require a certain level of literacy.

2.5.9 **Participation Scale**

The Participation Scale (Van Brackel et al, 2006a) was developed for use in Nepal, India and Brazil and includes the following attributes as part of community integration:

- Relationship, refers to general relationship to self, and others including being respected by others and meeting new people.
- Community life refers to getting involved in community or civic activities like attending meetings in the community, bazaar or nearby village, visiting other people in the community.
- Recreation and leisure refers to being socially active i.e. being able to take part in casual recreational and social activities e.g. sports, religious.
- Education,
- Work refers to whether the person has the same opportunities to find work and also the ability to work as hard as peers do.
- Economic refers to the ability to contribute economically to the household.
- Assisting others, this refers to helping others but does not specify the kind of help that is given e.g. physical.

This outcome measure was developed to measure social participation for use in rehabilitation, stigma reduction and social integration programmes. The main reason for developing this participation scale was the desire to have a tool that would cover all domains of the

participation component of ICF for use in low and middle-income countries (Van Brackel et al., 2006b).

The scale has 18 items, which are scored as “yes”, “sometimes”, “no”, “irrelevant” in comparison to the respondent’s peer, the respondent needs to quantify the magnitude of the problem by classifying the problem as 1 = no problem, 2 = small, 3 = medium and 4 = large problem. The scores are added up and the participation restriction is graded as follows:

- 0-12 -No significant restriction
- 13-22 -Mild restriction
- 23-32 -Moderate restriction
- 33-52 -Severe restriction
- 53-90 -Extreme restriction

The PS appears to be an ideal scale to assess community reintegration in that it includes all domains of participation according to the ICF, it is interview administered and was developed in developing countries Nepal, India and Brazil which have similar characteristics to South Africa. The limitations of this OM are its length and constant comparison of the interviewee to his/her peers, which may be confusing to the respondent. The Participation Scale may also have an element of redundancy to it. It has 18 questions in two parts. Part one inquires whether the person has had opportunities equal to those of his/her peers. If the answer is “sometimes” or “no” there is a follow up question: “How big a problem is it to you” and the respondent can select either of the following options “small, medium or large problem”. However, it seems the same follow up question is used in cases where the person answered “irrelevant or I do not want to”. It may be that respondents are reluctant to answer any questions that are not relevant to their life. To date the PS’s validity and reliability has not been tested on a population of patients with stroke.

2.5.10 Other Outcome Measures that are being used to Assess Part of Community Integration in Patients who have had a Stroke:

- The EurolQol Quality of life Scale, commonly known as the **EQ-5D**, is a generic health status questionnaire of which one of its domains assess mobility and usual activities but the rest of the items in this domain assess impairments (Salter et al., 2005b). The major limitation with the use of this OM is that part B of the scale uses a VAS, a major problem and abstract concept to explain to people who have a low educational level. The other limitation is that it is not suitable for use in serial assessment of individual patients; it is

more appropriately used in the study and comparison of groups (Dorman et al., 1998, Essink-Bot et al., 1997).

- The Medical Outcomes Study Short Form 36 **(SF-36)** is a generic health survey, created as part of the Medical Outcomes Study to assess health status in the general population (Ware and Sherbourne, 1992). It consists of eight subscales, two of which assess participation namely: role limitation-physical and social functioning. The limitations are similar to the Euro-Qol, in that it is not suitable to use for serial comparisons of individuals but rather in larger group comparisons only (Dorman et al., 1998). It is also self or telephone-administered by a trained interviewer. The last limitation is that you need to buy a licence to use it.

- The Nottingham Health Profile **(NHP)** was designed to be a brief, subjective measure of perceived health encompassing the social and personal effects of illness (Hunt et al., 1985). It is somewhat limited in its measure of participation per se, as it only contains one domain of five items assessing social functioning (Salter et al., 2005c).

- The Stroke-Adapted Sickness Impact Scale Profile **(SA-SIP-30)** is a comprehensive, behaviourally-based measure of perceived health status originally intended for use as a generic health status survey. It only has one subscale that assesses participation called “social interaction”. Its major limitation is that it contains items that assess body structure/function and some activities but very few items that assess community reintegration. The second limitation is the lengthy time it takes to complete this scale, although a shorter version has been developed for use in stroke outcomes research.

- Hale et al, 2002, developed the Soweto Stroke Questionnaire **(SSQ).** The purpose of this questionnaire was to identify problems experienced by patients with stroke living in Soweto. The questionnaire needed to cover aspects of impairment, disability and handicap including quality of life (Hale et al, 1998b). Although the questionnaire was developed for patients that have similar characteristics to the urban cohort of this study it excludes patients in the rural setting and, the other major limitation is that it contains items that assess body structure/function and some activities but very few items that assess community reintegration.

2.5.11 Conclusion on Definition and Components of Community Reintegration

In summary the definition and components of community reintegration vary and differ depending on the setting and target population. Although there are similarities amongst the different measures, differences occur in the definition and components of community reintegration based on contextual factors. Except for the PS all the outcome measures reviewed were formulated in more affluent and developed countries. Some scales were considered by the author to be too long for use in a largely illiterate population where questionnaires are better interviewer administered (CHART, SIS, PS, SA-SIP-30). Many scales were scored based on the VAS system and some use a five or more point Likert scale, which as explained previously is an abstract concept for people with low educational levels and does not lend itself easily to translation (RINL, LHS, SIS, CIM, SS-QOL, SIPSO). Only six scales have been validated in a stroke population (RNLI, LHS, SS-QOL, SIPSO, SIS, SSQ and SA-SIP-30)

Many scales were not specific to community reintegration and only included very few items under the participatory domain (RNLI, LHS, SS-QOL, SIS, SSQ, NHP, EQ-5D, SF-36, SSQ and SA-SIP-30). Based on this review of the tools developed to measure community reintegration, there does not appear to be a tool that is appropriate to measure community reintegration following stroke in a black South African community; a measure that takes into account contextual, cultural, multi-lingual and illiteracy factors. As a result, the researcher set out to develop an outcome measure of community reintegration that would take into account all the environmental and personal factors of patients with stroke living in poor socioeconomic rural and urban areas of South Africa.

Outcome Measures need to be systematically and methodically developed; the next section explores what this development requires.

2.6 THE DEVELOPMENT OF AN OUTCOME MEASURE

The use of outcome measures in health care is to enable total clinical quality management (Cole et al, 1995) which forms part of the quality assurance process. "*An outcome measure is defined as a measurement tool e.g. an instrument; questionnaire or rating form used to document changes in one or more patient characteristics over time"* (Cole et al, 1995: 5-6). The purposes of an outcome measure are to (1) identify what the patient's ability is at baseline, (2) to document progress, (3) to measure change and (4) to enhance clinical decision-making about the patient and the rehabilitation programme. In order for therapists to provide holistic

rehabilitation, outcome measures need to be appropriate at every level of the patient's rehabilitation process.

"Outcome measures are used as data collection methods for educational and research purposes. OM's help to gather information on knowledge, attitudes, opinion, behaviour, facts and other information which could be used to make decisions about a particular situation". Development of a valid and reliable OM involves several steps and takes considerable time in order to reduce measurement error (Radhakrishna, 2007). Measurement error is defined as "*the discrepancy between respondents' attributes and their survey responses*" (Groves, 1987: 156-172). Each step depends on the fine tuning and testing of previous steps that must be completed before the next step. If the researcher follows the five steps in the development and testing of questionnaires/instruments described below then data quality and the utilization of outcomes measure will be enhanced (Radhakrishna, 2007).

Step 1: Background

In this initial step, the purpose, objectives and research question are examined. It is in this stage where the participants, their background and especially their level of education, access to these participants and the process used to identify them are explored and explained.

Step 2: Conceptualization

After developing a thorough understanding of the background of the population in question, the way forward is to decide how this information is going to be collected. A link among the objectives of the study and their translation into content is established in this step (Radhakrishna, 2007).

Step 3: Format and Data Analysis

Until recently OM's were developed with little or no consultation with the population in question. Consultation is becoming increasingly important especially with the notion of wanting to produce services that are relevant and appropriate. According to Radhakrishna, (2007) in step 3, the focus is on writing statements or items or questions of the construct being measured. These items should be developed in consultation with the population in question and/or experts as well as the literature. In this step selection of appropriate response scales, questionnaire layout, format, ordering, font size, front cover, appendices and proposed data analysis i.e. interpretation of the measure, should be decided upon.

Step 4: Establishing Validity

As a result of steps 1 to 3, a draft questionnaire/instrument is ready for establishing validity. Validity addresses the amount of systematic or built-in error in measurement (McDowell and Newell 1987; Norland 1990; Streiner and Norman 2003). There are many types of validity, these are described below and the use thereof depends on the objectives of the study.

"Face validity *indicates, whether on the face of it, the instrument appears to test/assess what it is supposed to test or the desired qualities"* (Streiner and Norman, 2003: 5, 66-67). This validity is established by clearly defining the concept that is being measured which in this study is community reintegration.

"Content validity *indicates whether the instrument samples all the relevant or important content or domain. The ability of an instrument to measure an abstract construct and the degree to which the instrument reflects the theoretical components of that construct"* (Streiner and Norman, 2003:5). This validity is established by checking the contents of the outcome measure. The content should contain all the elements that reflect the variables of the construct that are being measured i.e. in this case community reintegration following stroke in the context of rural and urban South Africa. Content validity is closely linked to face validity, and both consist of a judgment by experts whether the scale appears to be appropriate for the intended purpose.

To further demonstrate the validity of an instrument, one needs empirical evidence to show that the tool or instrument is measuring what is intended. Construct validity becomes the solution to producing the empirical evidence. According to Streiner and Norman, (2003), "Construct validity *indicates that items that make up an instrument, adequately samples the universe of the content that defines the variable being measured".*

The two methods of establishing an outcome measure's construct validity are convergent or divergent validation and factor analysis (Streiner and Norman, 2003). Firstly if another scale with the same or similar attributes is available, then an obvious approach is to administer the experimental instrument or newly developed OM and one of the existing instruments to a sample and see whether there is a strong correlation between the two. This approach is described by several terms in the literature including convergent, criterion and concurrent validity (Norman and Streiner, 2003). Divergent or discriminant validity on the other hand is established by comparing the new measure to an existing outcome measure and poor correlation between the two measures would be found.

The second method of establishing validity is through factor analysis (FA) and below is the explanation: *Factor analysis is a data reduction technique. It is not designed to test a hypothesis or tell you whether one group is significantly different from another. It takes a large set of variables and looks for a way in which the data may be reduced or summarised using a smaller set of factors or components. This is an almost impossible task to do by eye with anything more than a smaller number of variables (SSPS, 200:179-199).*

Researchers involved in the development and evaluation of tests and scales use FA extensively. The scale developers starts with a large number of individual scale items and questions and, by using factor analytic techniques, they can refine and reduce these items to form a smaller number of coherent domain or subscales (SSPS, 2007: 179-199). The number of patients (sample size) to include in such research depends on the number of items in the questionnaire. For example, Nunnally (1994) recommends a minimum of 10 respondents per item for factor analysis. Boyle (1985) takes the more stringent position of 20 respondents per item for factor analysis.

There are three values to use when using factor analysis, the Eigen value, which reflect the amount of variance accounted for by each factor. Factor loadings, which represent the correlation between each item and each factor and lastly rotations are done to identify meaningful factors that include highly correlated items of the factor. Usually a factor loading of 0.30 or less is not meaningful (Kielhofner, 2006).

Step 5: Establishing Reliability

Reliability refers to random error in measurement. Reliability indicates the accuracy and precision of the measuring instrument (Norland, 1990) and seeks to answer the question; does the questionnaire actually measure what it purports to measures? A first step in providing evidence of the value of an instrument is to demonstrate that measurement of individuals on different occasions or by different observers or by similar or parallel tests, produce the same or similar results (Streiner and Norman, 2003).

There are a number of ways in which reliability can be established. Internal consistency is when an outcome measure is administered once, in order to measure the extent to which all of the items making up the scale measure the same construct. Internal consistency is generally measured by a Cronbach coefficient. Acceptable reliability of instruments developed for research purposes can be as low as 0.60 although 0.80 is a generally accepted threshold for internal consistency (Streiner and Norman, 2003).

Stability on the other hand examines the reproducibility of a measure administered on different occasions (Streiner and Norman, 2003). The different types of reliability are test-retest, inter-rater and intra-rater reliability. Test-retest reliability is a measure of how consistent scores are across time. It was measured by the Pearson correlation coefficient in the past but the interclass correlation coefficient (ICC) is currently used as it takes into account not only group differences but individual differences (Kielhofner, 2006). The outcome measure is considered reliable if the ICC coefficient value is close or equal to one i.e. any value between the range of 0.0-1 is considered reliable, indicating perfect reliability or absence of error; conversely, zero representing an instrument is full of error. Intra-rater reliability measures the consistency of the same assessor for the same patients assessed on two separate occasions, whereas inter-rater reliability measures the consistency between two assessors for the same patients assessed at the same time (Streiner and Norman, 2003).

The last step in the development of an OM is the translation process from one language to the other.

2.6.1 Translation of Outcome Measures from English to Local Languages

Translation of measuring instruments is necessary when the tool was developed in a different language, culture and context to that to which it is to be applied. Berkanovic, (1980) highlighted that the problems with translating measurement tools without rigorous back-translation and pretesting, the instrument may be interpreted differently in the new language. Even if the translation is adequate, cultural differences can adversely affect an instrument's properties (Deyo, 1984). To be fully confident of an instrument's validity in a new language or culture, a complete repetition of the validation process is required (Nord, 1991).

Due to the high illiteracy rate, different cultures and languages used in South Africa, outcome measures written in English need to be translated into a variety of local languages. In South Africa 32% of the adult population are regarded as being functionally illiterate and of this percentage the black South African illiteracy rate is over 20% (Aitchison & Harley 2004).

Grebe (2009), in a study to investigate the use of the Owestry Disability Index (ODI) in a Zulu speaking population in Soweto (South Africa), concluded that a significant number of the target population needed assistance in filling in the English ODI. South Africa has 11 official languages (Statistics South Africa, 2001). Only 12% of the Gauteng population speak English as their first language (Big Media Publisher, 2010). Zulu is the most common language with

21% of the population using it as their home language followed by Sesotho 13%. Language barriers are thus a legitimate problem when conducting research hence the issue of translating outcome measures is pertinent to avoid prejudicing the patient especially when the outcome measures use terminologies and concepts that are foreign to the context of the patient being assessed (Akinpelu et al., 2007). Beaton et al. (2000) suggest guidelines for the process of cross-cultural adaptation of self reports measures. These steps will be discussed as part of the methodology in appropriate chapters of this thesis. Below some of the methodological issues and approaches used in this study are discussed.

2.7 METHODOLOGICAL APPROACHES

In order to ensure that a newly developed outcome measure is valid it needs to be underpinned by the opinions and experiences of those for whom it is to be developed. This initial step of this thesis necessitated a qualitative methodological approach.

Qualitative research is a means of exploring and understanding the meaning individuals or groups ascribe to a social or human problem. The process of research involves emerging questions and procedures, data typically collected in the participant's setting, data analysis inductively building from particulars to general themes, and the researcher making interpretations of the meaning of the data (Creswell, 2009). Evidence-based physiotherapy which is informed by relevant, high quality clinical research and integrated with patients' preferences and perspectives, practice-generated knowledge and other factors (Hebert et al., 2005) needs a deep contextual understanding of the behaviour of people, patients and health professionals, in specific settings and interactions. Such topics are the focus of interpretivist studies using qualitative methods of research inquiry (Richardson and Lindquist, 2010).

The collection of qualitative data in evaluation, inquiry or research is common. Recently it is important that the populations for which the OM is being developed be involved and included at different stages of the development of an OM. However, knowledge about strategies for efficient and defendable procedures for collection and analysing qualitative data is less common (Thomas, 2006). Peers, grant reviewers and readers evaluate the worth of any research endeavour, regardless of the approach taken. Most quantitative researchers recognise and document the worth of a project by assessing the validity and reliability of the work (Payton, 1979). This same attention to the merits of a study, however, is much less common in qualitative research (Krefting, 1991).

Tong et al., (2007) proposed a 32-item checklist (consolidated criteria for reporting qualitative research (COREQ) for assessing the quality of studies that use interviews and focus group data collection. This checklist looks at different factors that need to be considered in developing, conducting and describing qualitative research. These factors include (1) the description of personal characteristics of the participants and the relationship of the participants with the researcher. (2) The study design, which should include the theoretical framework, participants selection, the study setting, as well as data collection strategies (3) and the analysis and presentation of findings. This includes how data were coded, the description of the coding as well as inclusion and presentation of quotations from the participants (Tong et al., 2007)

Data saturation is another step to consider in qualitative research. Data saturation is the key to excellent qualitative work, but at the same time it is noted that there are no published guidelines or tests of adequacy for estimating the sample size required to reach data saturation (Guest et al., 2006). The data are considered saturated when no new information is surfacing during subsequent interviews (Strauss and Corbin, 1990; Polgar and Thomas, 2008). The point of saturation is normally dependent on the issue being investigated, the experience of the researcher and the objectives of the study (Hobart et al, 2001; Trigg et al, 2000).

The last step and factor to be considered in qualitative research is the method of analysis of qualitative data. Qualitative data analysis refers to the processes by which researchers organise the information collected and analyse the meanings of what was said and done by the participants (Polgar and Thomas, 2008: 245).There are many methods of data analysis in qualitative research. These methods are dependent on the objectives of the study and the method used in data collection. One such method of analysis is thematic content analysis (TCA), which is a descriptive presentation of qualitative data.

In order to ensure that the researcher adheres to these guidelines when conducting qualitative research Guba (1981) proposed a model for assessing the trustworthiness of qualitative data. Trustworthiness is established with strategies used both by researchers to increase the rigour of qualitative studies and readers of such research in assessing the value of the findings (Krefting, 1991). Guba's (1981) model is based on the identification of aspects of trustworthiness that are relevant to qualitative studies namely credibility (truth value), transferability (applicability), dependability (consistency) and confirmability (neutrality).

Credibility establishes how confident the researcher is with the truth of the findings based on the research design, informants and context. This is usually obtained from the discovery of human experience as they are lived and perceived by informants. Some of the strategies that can be used to increase credibility are: prolonged and varied field experience (length of time spent in data collection and spending enough time with participants in order to be able to arrive at the conclusion) and keeping a field journal. A field journal is used for a variety of reasons, for example to capture the non verbal cues from patients this then completes the whole picture of the interview, captures the process step by step and lastly it informs about the influence of the physical environment (Mulhall, 2003).

Transferability refers to the degree to which the findings can be applied to other contexts and settings with other groups; it is the ability to generalize from the findings to the larger population. Guba (1981) refers to applicability as transferability. The strategies used to ascertain transferability are comparison of sample to demographic data, time sample (a sample selected at a particular time of a phenomenon) and dense descriptions of the findings. Though qualitative results cannot be generalised per se, as they are often based on small samples, inferences can be made from the findings. The third criterion to assess trustworthiness is dependability, which is referred to as the consistency of the data, i.e. whether the findings would be consistent if the enquiry were replicated with the same subjects or in a similar context.

The first step in the development of the new outcome measure of community reintegration was to identify what people with stroke considered to be important with regards to community reintegration. A qualitative methodological approach was used in this step. On the basis of the findings a draft questionnaire was developed. The questionnaire was then presented to a group of experts and patients to validate. For these steps Delphi and nominal group techniques were used to reach consensus amongst neurological and community based therapists (experts) as well as patients and their caregivers. Below the description of these two techniques is given.

2.8 CONSENSUS METHODS: THE DELPHI AND NOMINAL GROUP TECHNIQUES

2.8.1 Delphi Technique

The use of the Delphi technique, as a research technique by physiotherapists has increased over the last decade (Hale and Eales, 2001; Cook et al., 2006; Raine, 2006; Myezwa, 2009; Roberts, 2009; Rushton and Moore, 2009). The Delphi technique is reported to be a useful research tool to obtain consensus of opinion on a specific topic from a chosen group. Gupta

and Clarke (1996: 185-211) describe the primary purpose of the Delphi to be *"a method to obtain the most reliable consensus of opinion of a group of experts"*.

The group should be selected on their recognised experience, qualifications and suitability in terms of expert knowledge and practical involvement with the issue being studied (Raine, 2006). Appropriate selection of the group contributes to face validity while consensus contributes to the construct and content validity (Raine, 2006). Within the literature, there is no guidance to be found on an acceptable group size. Wide ranges of group size have been reported (Raine, 2006). Smaller groups have been reported to achieve good results due to a low dropout rate and ease of follow up. Homogeneity of the group is also reported to contribute to good results (Ziglio, 1996).

The number of rounds to reach consensus depends on the objective of the study; most physiotherapy studies report up to a third round (Cook et al., 2006; Myezwa, 2009; Raine, 2006; Roberts, 2009; Rushton and Moore, 2009), except for Hale and Eales (2001), in their study consensus was reached at the end of round two. In the study by Raine (2006), consensus was reached in the fourth round.

To report if consensus has been achieved the percentage of agreement between participants is reported and generally thought to be acceptable if it is between 60 and 80% (Sumison 1998, Green et al., 1999, Hasson et al., 2000, Deane et al., 2003), although some authors have suggested a lower rates of 51% consensus amongst participants (Loughlin and Moore, 1979; McKenna, 1994). Crisp et al., (1997) questioned the value of using percentage measures; as they suggested that the stability of the response through a series of rounds is a more reliable indicator of consensus. In the different physiotherapy studies using the Delphi technique to date the level of consensus was set to be between 70 and 80% (Hale and Eales, 2001; Cook et al., 2006; Raine, 2006; Myezwa, 2009; Roberts, 2009; Rushton and Moore, 2009)

Some of the advantages of the Delphi technique are that the technique allows a group of people with expertise in different geographic locations to give their opinion and gain consensus on a particular problem in a manner that is free of bias while being informed about other people's opinions (Vazquez-Ramos et al., 2007). Its disadvantages include: (1) there is potential for poor execution through poorly designed questionnaires (Vazquez-Ramos et al., 2007: 111-118). (2) the poor selection of the experts where a narrow perspective may be the result, (3) unreliable result analysis, (4) limited value of feedback and (5) consensus as well as instability of responses in consecutive rounds (Gupta & Clarke, 1996). The Delphi technique is

time-consuming and may result in participant's fatigue (Gupta & Clarke, 1996; Vazquez-Ramos et al., 2007). A further methodological weakness influencing the integrity of the results is that the participants' answers may be influenced by the groups' results as the rounds proceed and this may result in a regression to the mean (Vazquez-Ramos et al., 2007).

Although the researcher acknowledges the weakness of this technique, he considered the Delphi technique to be a good way of collecting data from the relevant and appropriate experts without geographic limitations. As well as gaining expert opinion on the development of an outcome measure, information from people representing the population of interest is equally important and should be solicited. The nominal group technique was used to obtain inputs from black adults with stroke, as it is explained below.

2.8.2 **Nominal Group Technique**

Fink et al., (1984) describes the nominal group process as "*a structured meeting that attempts to provide an orderly procedure for obtaining qualitative information from a target group who are most closely associated with a problem area" (Fink et al., 1984: 979-983)*. The nominal group technique uses a highly structured meeting to gather information from relevant experts or people who have an interest in, or who are affected by (usually 9-12 in number) a given issue. It consists of two rounds or meetings in which panellists rate, discuss, and then rerate a series of items or questions (Jones & Hunter. 1995). Patients can also be used as experts in nominal group meetings. By virtue of the experience of living with a condition, they are deemed experts and can assist with decision making.

The nominal group technique focuses on a single goal (Jones & Hunter 1995). The method was developed in the United States in the 1960's and has been applied to problems in social services, education, government and industry (Fink et al., 1984). In the context of health care the method has most commonly been used to examine the appropriateness of clinical interventions but has also been applied in education and training, in practice development and for identifying measures for clinical trials.

The use of the nominal group technique in physiotherapy research has been documented in several studies using expert participants (Potter et al, 2003a; Jackson et al, 2009; Rushton and Moore, 2009) but it has only been used once with people who have the condition and interest (Potter et al, 2003b).

In a nominal group technique, it is difficult to report the level of agreement. This is due to various reasons, one of them being the objectives of the study. There is no single way to report if consensus has been achieved (Delbecq et al, 1975). Potter et al (2003a) used qualitative methods to come up with the level of agreement, as their study was qualitative in nature. They used patients' quotes to support the agreement made (Potter et al, 2003a).

In nominal group technique, the number of meetings varies from one to three depending on the objective of the study. Some studies used one meeting (Potter et al, 2003b); others two meetings (Potter et al, 2003a; Jackson et al, 2009) others three meetings (Rushton and Moore, 2009), whilst other four (Hauskoos et al, 2009) depending on the objectives of the meetings. For example in the study by Hauskoos et al, (2009) to develop a set of agreed upon knowledge gaps and priority related to HIV and sexually transmitted infections (STI) prevention in the Emergency Room (ER), the four meetings included experts working alone firstly to generate ideas about the topic being discussed, secondly sharing of ideas with other experts about the topic being discussed, thirdly discussion of these ideas and lastly voting and ranking. This thus confirms the fact that the number of meetings depends on the objectives of the study.

Some of the advantages and disadvantages of the nominal group technique are similar to that of the Delphi technique. Similarities include that the technique allows a group of people with expertise, albeit it in a face to face setting, to give their opinion and to gain consensus on a particular problem. Disadvantages include a potential for poor execution through crudely designed questionnaires and poor composition of the group. There is a possibility of bias in the nominal group and participants can influence each other especially when there is a very strong character in the group (Fink et al., 1984).

2.9 CONCLUSION

Stroke brings with it many participation restriction problems that can affect community reintegration for both the individuals with stroke and their caregivers. To assist the rehabilitation process to improve participation and reintegration appropriate outcome measures should be used to assess community reintegration and these measures should take into account the context of the patient's environment.

The available outcome measures to assess community integration are inappropriate for use with black South Africans living in poor or low socioeconomic areas, as these measures do not take into account contextual, cultural, multi-lingual and illiteracy factors in South Africa. Therefore, there is a need to develop appropriate measures. A systematic approach should be

used to develop such an outcome measures that follows a rigorous process of development, and includes consulting the population in question and establishing the psychometric properties of the measure.

The next chapter describes the first study of this thesis, undertaken to conceptualise community reintegration from the perspective of patients' as well as their caregivers and to develop the preliminary framework of the outcome measure.

CHAPTER 3

3. STUDY 1: QUALITATIVE STUDY

CONCEPTUALISATION OF COMMUNITY REINTEGRATION AND THE DEVELOPMENT OF THE PRELIMINARY OUTCOME MEASURE

3.1 INTRODUCTION

The results of this Study 1, assisted in the development of a preliminary outcome measure to assess community reintegration for patients with stroke in South Africa. Study 1 had two parts; the first was to conceptualise community reintegration from both the perspective of patients who have had a stroke and from their caregivers. The second was to develop and construct an outcome measure to be used and further developed in the second study of this thesis. This chapter presents the method and results of a qualitative study that was undertaken with patients with stroke and their caregivers (including a pilot study conducted to underpin the qualitative study). The chapter will present the themes that emerged from the interviews that were used to generate the questionnaire and the newly developed outcome measure. The definition of community reintegration as discussed in the literature review in chapter two demonstrated that community reintegration is very context specific. Therefore, this chapter will assist in defining community reintegration from the perspective of patients with stroke and their caregivers in poor socioeconomic rural and urban areas of South Africa.

3.2 PILOT STUDY

3.2.1 Introduction

This section will describe the pilot study that was conducted to provide a framework for the qualitative study (Study 1).

The **objectives** of the pilot study were:

1. To trial and time the length of the interview for Study 1.
2. To check any ambiguity in the questions contained in the interview schedules.
3. To train research assistants in interview techniques for Study 1.

3.2.2 Study Setting

The pilot study took place in a community setting in primary health care (PHC) clinics and patients' homes in both urban (Gauteng province) and rural (Limpopo province) settings.

3.2.3 Patient Recruitment and Ethical Consideration

Patients were recruited from PHC clinics in Soweto in Gauteng province, South Africa. These patients were selected as representing the views of an urban community cohort. Patients representing rural views were recruited from PHC clinics and villages around the Elim and Siloam areas in Limpopo province. In both provinces, the patients were selected from clinics that would not be recruited for Study 1. The respective provinces and clinic managers were asked for permission to carry out the study (see Appendix 1.2, 1.3, 3.1 3.2 and 3.3). Once permission was granted physiotherapists working in these clinics were approached to provide the researcher with a list of patients with stroke attending the clinic as well as those they were visiting at home. The resident therapist initially approached patients and caregivers to ask them individually to participate in the study. Patients and caregivers were given the information sheet and if they agreed to participate in the study were asked to sign the study consent forms (see Appendix 3.4 and 3.5).

3.2.4 Sample and Inclusion Criteria

The inclusion criteria were patients who had sustained a stroke who were aged 18 years and over. In the case of patients with expressive or receptive aphasia only the caregiver was interviewed with the permission of both the participant and caregiver. Patients were members of the community in which they had lived pre-stroke and had been back living in their community for six to twelve months since their stroke. Six months to one year has been found to be an adequate period for reintegration into a community following stroke (Stark et al, 2005).

3.2.5 Patients were Excluded if They:

- Had been admitted to a nursing home,
- Were aphasic and had no local family carer- (in South Africa patients with stroke are mostly cared for at home by family members and not paid support workers).
- Were medically unstable (self report)
- Had major medical problems not related to stroke (self report)

3.2.6 Method

3.2.6.1 Procedure for training of research assistants

The research assistants in the rural areas were physiotherapists who were born and bred in the same area, spoke the local language and knew the customs very well. The researcher was the only person collecting data in the urban area.

Training of research assistants regarding data collection of the pilot study in the rural areas was done prior to the commencement of the study. The topics for training included the following:

- The aim of the whole study and how the pilot study fitted into the whole study.
- Ethical issues: obtaining consent.
- The importance of obtaining demographic data before the interviews.
- To operate the audiotape.
- The art and process of interviewing including the use of an interview guide/prompt and follow up questions when information is insufficient.
- The use of local language in the interviews.
- At the end of the session the research assistants were given the opportunity to clarify anything of which they were unsure.

In pilot study, the research assistants sat in one interview to practically observe and learn how to conduct interviews before commencement of study 1.

3.2.6.2 **Procedure for pilot study interviews:**

- Prior to the interviews, consent for participating in interviews and audio taping was sought from either the patients or caregivers (see Appendix 3.4 and 3.5).
- Demographic data were captured on a separate sheet to interview scripts.
- The languages used in the interviews were Zulu and South Sotho in Gauteng province; TshiVenda and XiTsonga in Limpopo province.
- Semi structured face to face interviews were used for data collection using open ended and probing questions (see Appendix 3.9 and 3.10).

The interview guide/prompt is discussed below.

3.2.6.3 **Development of the interview guide/prompt:**

Questions were generated from the literature (Pilkington, 1999; Trigg et al., 2000). The questions were chosen to cover aspects of the patient's life before and after the stroke, included an ice breaker to relax the patient. The following questions were included and asked as an interview prompt for the pilot study:

1. Tell us about your family
2. When did you have a stroke?
3. What caused your stroke?
4. What corrective measure(s) did you take? What did you do to correct your stroke?
5. What do you understand stroke to be? Or what is a stroke?
6. How long have you been staying in this community before and following the stroke?

7. Can you please describe a typical day? How do you fill/spend your day?
8. Has your life changed following the stroke? Please explain the changes to me.
9. Do you think that you have settled back into your community well following the stroke? Please explain
10. Can you please explain how the changes you have experienced as a result of the stroke have affected your settling back into the community following the stroke?

The interviews were undertaken by the researcher and research assistants; and were audio taped. After the interviews, patients were given an opportunity to listen to the recording and make any necessary changes. Finally, all patients and family members were thanked for their participation and contribution to the study and informed of the next steps to be taken following the interview, which was validation of the outcome measure.

3.2.7 **Analysis**

The interviews were fully transcribed word for word in the language spoken in the interview and translated to English by the researcher (physiotherapist) and a research assistant (physiotherapist) who spoke the language fluently. A thematic content analysis was done. The transcripts content were analysed according to Tesch's (1992) method in order to identify the emerging themes that define community reintegration from the patient's perspective by reading through the transcripts multiple times. In order to establish themes, common concepts were first identified and the concepts were reduced into categories. The categories were reduced to themes.

3.2.8 **Results**

Five patients were recruited and interviewed (Two from the rural area and three from the urban area). None of the patients was aphasic therefore no caregiver was interviewed. The interviews took about 45 minutes to 1 hour, 30 minutes depending on the way the patients/caregiver expressed themselves.

The table below presents the characteristics of the patients who participated in the pilot study.

Table 3.1: The Demographic Characteristic of the Participants for Pilot Study

Characteristic of participants	**Values (n=5)**
Age:	Mean age= 52 years, range 35-65 years
Gender:	Three females and two males
Access to caregiver: In SA when patients are discharged from a hospital they are taken care of by family at home not a paid carer.	Four had caregivers
Level of formal education obtained: School ends at year 12 (Grade 0-12)	Ranging from Grade four to tertiary level
Side of hemiplegia:	Two left and three right
Location of the interview:	One patient's home and four at a PHC clinic
Date of stroke: The interviews for study one took place from October to November 2007.	Ranged from 2000-2006
Employment and occupation status:	Four of the patients were unemployed, One was a pensioner Four who were unemployed, their previous occupation included general worker, painter, grinder, and carpet/tile fitter. One was a teacher.
Marital status:	Two of the patients were married, two single and one lived with a partner.
Period living in the community:	All the patients in the pilot study had been living in the community from before the stroke for a period ranging from a year to their whole life.

3.2.8.1 **Summary of the emerging themes from the pilot study**

The themes emerging from the pilot study were threat to livelihood, loss of meaningful activities and restriction in mobility within their own homes and community. The participants in the pilot study saw community reintegration as being able to be incorporated in daily home and, community activities as well as still being able to live a productive life.

3.2.8.2 **Conclusion of the pilot study and recommendations for study 1**

All the interviews went well and questions to be used in the interview were largely understood except for one question. This question was changed as it confused patients and it could not easily be translated to local languages used in the interviews:

- 10. "Can you please explain how the changes you have experienced as a result of the stroke have affected your settling in the community following the stroke"?

The confusion was picked up early on in the pilot study interviews (3rd) and was thus replaced by the following question:

- "What activities or things would indicate that you have settled back well into your community following your stroke"?

This question was viewed as very important as it was used to help in defining community reintegration from the perspective of patients as well as their carers when data were analysed.

The questions below were removed from the interview schedule as they did not help in answering this study's objective and did not deal with community reintegration.

- 5. What is a stroke?
- 3. What has caused your stroke?
- 4. What was done to correct your stroke?

These questions below were removed as they were already contained in the demographic data sheet.

- 2. When did you have a stroke?
- 6. How long have you been staying in this community?

Therefore the final interview prompt/schedule to be used in study 1 had five questions (see Appendix 3.11 and 3.12):

1. Tell us about your family
2. Can you please describe a typical day? How do you fill your day?
3. Has your life changed following the stroke? Please explain the changes to me.
4. Do you think that you have settled back into your community well following the stroke? Please explain your answer.
5. What activities or things would indicate that you have settled back well into your community following the stroke?

3.2.8.3 **Summary of the training of research assistants**

The training went well and the process of interviewing was well understood and practically observed. The researcher stressed the importance of making sure that the audio tape recorder was working before each interview. With regards to the process of interviewing the researcher stressed the fact that patients need to be given enough time to respond to the questions asked and that follow up questions must be asked in order to get depth and to enrich the data.

3.3 STUDY 1: STAGE 1 FIRST ROUND OF INTERVIEWS

3.3.1 Method

3.3.2 Study Design

A qualitative study, using semi-structured, face to face interviews with patients who had had a stroke and their caregivers was conducted. This approach was adopted as it enabled patients and their caregivers to fully explain their perspectives and feelings about their reintegration into their communities.

3.3.3 Data Collection

3.3.3.1 Inclusion and exclusion criteria

The inclusion and exclusion criteria were the same as the pilot study.

3.3.3.2 Patient recruitment and setting

Patients were recruited from the major PHC clinics in Soweto namely, Chiawelo, Zola, Mofolo and Alexandra University clinic in Gauteng province, South Africa. These patients were selected as representing the views of an urban community cohort. Patients representing rural views were from recruited from clinics and villages around the Elim and Siloam areas in Limpopo province. The respective clinic managers were asked for permission to carry out the study in their clinics. Once permission was granted physiotherapists working in these clinics were approached to provide the researchers with a list of patients with stroke attending the clinic as well as those they were visiting at home. The resident therapist initially approached patients and caregivers to ask them individually to participate in the study. Patients and their caregivers were provided with a study information sheet and if they agreed to participate in the study were asked to sign the study consent form (see Appendix 3.6, 3.7 and 3.8).

3.3.3.3 Interviews

The interviews for Study 1 took place from April to November 2008. The interviews were conducted by the researcher and research assistants who were Black physiotherapists, living in the areas similar to the patients being interviewed and who therefore had an understanding of the socio-political, economical and cultural environment from which these patients came from.

Before each interview the researcher obtained demographic data from participants (see appendix 3.14). The interview was conducted by the researcher, in the language with which the patient was familiar. In the case of patients speaking languages that the researcher was not familiar with, a trained research assistant who spoke the appropriate language conducted

the interview. Semi-structured interviews were conducted using the developed interview schedule from the pilot study.

The interviews took place at the clinic for those who could get to the clinic and at home for those who could not come to the clinic. Patients were asked permission for the researcher to interview their caregiver if they are unable to speak due to the effects of the stroke. The interview was recorded on an audiotape. The patients were given the opportunity to listen to the recordings and make changes if they wished. This was done to ensure the credibility of the data. Each interview was scheduled for an hour and a half as required.

The face-to-face semi structured interviews included questions that were related to the patients' lives pre-stroke and after the stroke. The following introduction and questions adapted from the pilot study recommendation were asked as follows: The adapted interview prompt:

1. Tell us about your family
2. Can you please describe a typical day? How do you fill your day?
3. Has your life changed following the stroke? Please explain the changes to me.
4. Do you think that you have settled back into your community well following the stroke? Please explain your answer
5. What activities or things would indicate that you have settled back well into your community following the stroke?

At the end of the interview, patients and caregivers/family members were thanked for their participation and informed of the next step from the interview (validation phase). Sufficient numbers of patient were interviewed in both settings to ensure saturation of data (Strauss and Corban, 1990) no new data were emerging on subsequent interviews.

3.3.3.4 **Data analysis**

The interviews were fully transcribed word for word in the language spoken in the interview and translated to English by the researcher (physiotherapist) and a research assistant (physiotherapist) who spoke the language fluently. A thematic content analysis was done. The transcripts content were analysed according to Tesch's(1992) method in order to identify the emerging themes that define community reintegration according to the patients, by reading the transcripts multiple times. In order to establish themes, common concepts were first identified and the concepts were placed into categories. The categories were reduced to themes. The themes identified in the transcribed data were checked for reliability. A therapist with experience in conducting qualitative research who had not been involved in the study reviewed

the themes and independently coded the data. The two codings were compared and discrepancies were discussed and clarified. This process was necessary to ensure that the themes were understandable, exhaustive, mutually exclusive and independent (Strauss and Corban, 1990).

3.4 STUDY 1: STAGE 2 SECOND ROUND OF INTERVIEWS

3.4.1 Introduction and Rationale for Second Round Interviews

Following the analysis of the baseline data and the preliminary results it was obvious that there were certain themes that needed to be explored further to obtain more information. Therefore in order to verify and enrich the existing data and gain more insight a second round of interviews was conducted.

3.4.2 Selection of Key Interviews for Second Round Interviews

3.4.2.1 Identification of the second round interviews

The first round transcripts were read numerous times and sorted into two groups;

- Firstly the participants who had sufficient **depth or lacked depth but had topics** that would potentially bring out new categories and themes as well as enrich the existing themes.
- The second groups included those who had **depth and some potential to** bring out potentially new categories and themes.

In both the rural and urban setting two groups were identified to be re-interviewed. A total of 15 participants were chosen from both the urban and rural cohort groups to be part of a sample to participate in the second round of interviews (six from the urban setting and nine from rural setting). The reasons for choosing these participants can be seen in the table below:

Table 3.2: Participants Chosen and Reasons for Second Round of Interviews

Urban Cohort	Rural Cohort
The first participant, Interview 1 was chosen on the basis of his expression of loss of social involvement, threat to livelihood and restriction in the community. Secondly this participant expressed his interrupted interpersonal and intimate relationships.	Two participants were selected based on their loss of active leadership role in the community (Interviewees 3 and 4).
Interviewee 3 was selected on the basis of his interrupted informal social interactions including his willingness to now want to assist others who had strokes to achieve a different level of human interaction.	Interviewee 6 was selected on the basis of her interpersonal relationship with her in- laws regarding the social role of a woman in rural communities. Interviewee 16 was selected based on his limitation in community involvement including within the religious structures in his community and threats to his livelihood.
Interviewee 11 was chosen based on his loss of active leadership role in the religious community.	Interviewee 17 was selected based on his limitation in community involvement in talent identification of soccer player at a grass root level.
Interviewee 2 was selected on the basis of threat to his livelihood and social mobility restrictions that limited his leisure activity and recreation.	Interviewee 19 was selected on the basis of her increasing dependence on her grandchild, social role change and threats to her livelihood.
Interviewee 5 was selected on the basis of loss of social mobility or restriction.	Interviewee 5 was selected on the basis of her social role reversal and restriction in social mobility and subsequently affecting her community involvement in structures within the community.
Interviewee 13 was selected based on the social mobility restriction and her personal care i.e. grooming	Interviewee 11 was selected on the basis of her social role reversal change and loss of identity within her family.
	Two interviewees were selected on the basis of loss or restriction of social mobility which then affected their community involvement and dispensing their responsibilities in the community (Interviewee 8 and 15)

3.4.2.2 **Procedure**

The research assistants were informed of this outcome as they needed to follow up the selected participants to seek consent for follow-up interviews and suggest possible visit dates. An explanation was provided to the research assistants on interview prompts for each interviewee and reasons thereof were explained. The researcher was to be part of these follow up interviews to assist. Consent to interview was obtained for this second round of interviews. After each interview, patients/participants were given time to listen to the recorded information to make changes as they wished. All interviews were recorded, fully transcribed and translated by both the research assistants and the researcher. Interview prompts included the issues raised by the interviewee in the first round of interviews and the added relevant questions from the theme(s) that emerged from the first round of interviews (the themes are described in the results section below).

3.4.2.3 **Analysis**

Thematic content analysis was done as described above to identify new themes from this second round of interviews and to support or confirm the existing themes from round of interviews (stage 1).

3.5 RESULTS OF STUDY 1: STAGES 1 AND 2 (FROM BOTH ROUNDS OF INTERVIEWS)

3.5.1 Characteristics of the Patients and Interviews Conducted

A total of 32 patients were interviewed and the characteristics of the patients are presented in Table 3.3 below.

Data saturation is a point at which no new information or themes are observed in the data. In the first stage of study 1 (first round of interviews) data were saturated from the 10th participant, an additional three patients were interviewed to confirm data saturation for the urban cohort. The same was done with the rural cohort, as data became saturated when the 16th patient was interviewed; an additional three participants were interviewed to confirm data saturation for the rural cohort.

For the second stage of study 1 (second round of interviews) a total of six patients in the urban setting and nine in the rural setting were re-interviewed from the 32 patients who were interviewed in the first round (stage 1 of study 1).

Table 3.3: Demographic Characteristics of Participants for Study 1

Characteristics	Urban (n=13)	Rural (n=19)
1. Number of interviews conducted:	13 interviews conducted	19 interviews conducted
2. Age mean (range) years:	56 (27-78)	60 (35-79)
4. Gender:	Males (M): 11 and Females (F): 2	M: 5 and F: 14
5. Marital status:	10 were still married 2 were single 1 widower	4 were widows 12 still married 1 divorced 1 was single 1 was living separately from spouse
6. Date of stroke: The interviews for study one took place from January to November 2008.	Ranged from 1995 to 2008	Ranged from 2002 to 2008
7. Level of formal education obtained: School ends at year 12 (Grade 0-12)	Range: Grade 0-tertiary	Range: Grade 0-12
8. Side of the hemiplegia:	Left (L): 8 and Right (R): 5	L: 10 and R: 9
9. Location of interview:	13 in a PHC clinic	15 patients' home and 4 in a PHC clinic
10. Who was interviewed:	Patients: 10 and caregiver: 3	Patients: 14 and caregiver: 5
11.Employment and previous employment status	Twelve were unemployed and only one was a pensioner. The previous occupations of the 12 unemployed urban participants included housemaid, self employed, driver, gardener, motor mechanic, accounts clerk, upholsterer, sales representative in insurance industry, university student and sales assistant in the clothing industry.	Eight were unemployed and 11 were pensioners and of the eight who were unemployed, their previous occupations prior to their stroke included housemaid, housewife, farm labourer, professional nurse, teacher, security guard, self employed and production line manager.
12.Period living in the community following stroke	The period (in years) of patients having lived in the community pre-morbidly ranged from over a year to their entire lives.	The period (in years) of patients having lived in the community pre-morbidly ranged from over a year to their entire lives.
13.Access to a caregiver: In SA when patients are discharged from a hospital they are taken care of by their family at home not a paid carer.	All participants had access to caregivers and all caregivers were members of the family, including a child, a wife or a husband. None had medical training.	All participants had access to caregivers and all caregivers were members of the family, including a child, a wife or a husband. None had medical training.

3.5.2 **Emerging Themes**

The data analysis revealed seven themes, namely

- loss of community mobility or restriction in community mobility,
- social isolation,
- role reversal and loss of personal identity within the family and community,
- loss of role within the family and community,
- loss of meaningful activities of daily living,
- threat to livelihood (sustainable/productive livelihood),
- loss of hope.

These themes will be presented in more detail below:

3.5.2.1 **Loss of community mobility or restriction in community mobility**

Participants in **both settings** were unable to move around their homes let alone in the community. They expressed feelings of frustration, poor motivation and discouragement. These feelings were shared by most participants albeit to varying degrees and in different environments as some participants found it difficult to move in their own homes whilst others could move in their homes but found it difficult to move around in the community. One **rural** participant told of her distress at being confined to her home:

"*Yes, I do. I am always at home, I do not go anywhere. Where could I go? I am unable to walk. When I go out with other people they say I slow them down so it is better to stay at home. I am also afraid that I will fall when I walk with my walker. The roads are also not in a good condition, they are very rocky and uneven, not tarred. So I stay home all the time"*

For some participants it was difficult to move around in their small homes, as expressed by one **urban** participant:

"It is hard to move around the house, the house is small and lots of furniture is in the way, so I find it hard to move in the house. I prefer this corner all the time"

For other participants, constraints within the environment, limited community ambulation as this participant in the **urban** cohort explained:

"Yes, I am unable to walk properly when going down the slope or hilly areas when I come to the clinic"

Some participants were very aware of their disability and because of that, they did not want to be seen in public as expressed by one **urban** participant:

"I can't and I don't want to be seen like this (pointing at her body) in public"

The restrictions in mobility resulted in social isolation.

3.5.2.2 **Social isolation**

Participants felt cut off from the world as a result of their stroke and that their social relationships had deteriorated:

"*I cannot get up, my whole left side is not working, I find it difficult to do anything for myself, I really feel trapped in this body. I cannot go anywhere, visit family, neighbours, friends; I am forever locked in this room until my daughter comes back from work. I really feel all alone. I can't remember when last did I get out of this place"*

"I am really on my own; my children leave me here at home all the time"

The feeling of isolation made participants depend on other members of the family for activities of daily living and thus made them feel like they were a burden to everyone in the homestead as the care giver of a **rural** cohort participant said.

"She cannot get of bed out, I come all the way from my house to help her to sit, I find her waiting for me. She tries but it is difficult, she is like a baby. That is the reason why we leave her here in bed"

In certain instances, one **rural** participant felt that he was not isolated but rather controlled too much as decisions were made by his wife as can be seen below:

"…My wife controls me too much at home"

When asked what he meant by that he said:

"They think because I have a stroke I am not able to make decisions about my life, they do not let me do heavy tasks nor take long walks because they think I will get lost"

Another participant in the **urban** cohort expressed his social isolation but from an intimate relationship point of view in the following manner:

"I need to improve my relationship with fairer sex, I need sex"

One **urban** participant said the following to express his frustration with his social isolation:

"I also need to interact with people because people inspire"

Participants felt that the stroke had damaged their previous relationships and made it difficult to for them to form new relationships due to the social isolation, as illustrated by a quote from a **rural** cohort participant:

"I do not have anyone to go to but I also do not have anyone visiting me except for my family members"

Due to the feeling of isolation and not being able to move around, participants felt that their role in the community had changed or reversed as expressed by the next theme.

3.5.2.3 Role reversal and loss of personal identity within the family and community

Prior to having a stroke all participants had a role to play as a mother, wife, father, sister in law, and a grandmother and these roles were fulfilled within the structure of a family or community. Many participants were also involved in community roles. The many role reversals are illustrated by the following quotes from an old woman from the **rural** cohort and a man from the **urban** cohort:

"..*And mudding with cow dung I cannot do, it is done by my children"*

"I want to be like other grannies"

"…I am no longer a breadwinner in my house and that affect the decision I can or cannot make within the family. My wife now is the head of the family"

A young (age 35 years) female participant in the **rural** cohort expressed her frustration at not being able to fulfil her role as a daughter-in-law in the family as follow:

"Also with cleaning, if I do not have a mop I must go on my knees, when I move backwards on my knees, this leg (pointing at the weak leg) does not allow me. Soon my mother-in-law will advice my husband to divorce me because I am not able to fulfil my womanly duties". She further added*:*

"I am a woman so there are certain expectation of me from my in laws so if cannot do...(pause) they will ask him to divorce"

An old grandmother in the **rural** cohort expressed herself as follows:

"…I cannot carry heavy groceries in plastic bags, my grandson has to help me otherwise I do not bother going to buy groceries"

Due to role reversal and the loss in personal identity within the family most participants felt that their role in the community was also lost as expressed below by the next theme.

3.5.2.4 **Loss of role within family and community**

The idea of loss of personal identity was described through a variety of experiences.

A caregiver said of his father-in-law (who could not talk due to expressive aphasia) who had lost his role in a **rural** community:
"He was part of the community leaders, tribesman, they would not have a meeting (Imbizo) without him. He was an advisor at the chief's kraal (Khoro). He was very good in meetings, he participated well. If there was anything that the community needed from the chief they would send him, things like funerals. He was headman, yes, he was a messenger, when people wanted or needed something or to get a message to the chief, they would send him"

Another **rural** participant told of his previous status within the community, which he had now lost expressed himself as follows:
"I am a chairperson of School Governing Body; I am also number 3 chief advisor and also a committee member of our community policing forum. I am also a treasurer of the businessman association of our area"

Other participants had prestigious roles, such as religious leaders and chairpersons:
"*I was an evangelist, home cell leader for our church then a church elder, then a pastor, these entire roles I fulfilled well before I had a stroke"*

"I was also a chairperson of a number of community organisations and social clubs e.g. the brotherhood (is a burial social club)"

A significant number of patients were not able to resume their previous activities. Their participation in daily living, community and social roles were therefore restricted, limiting many various meaningful aspects and activities of their lives as expressed in the theme below.

3.5.2.5 **Loss of meaningful activities of daily living**

Participants in both cohorts expressed their loss of ability to undertake meaningful activities, when asked to explain their typical day or rather how they spent their day. Almost all participants said they did nothing all day other than watch television, just sitting or sleeping. When asked about their previous lifestyle it became very clear that these participants were not participating in activities they liked doing. Most women in the **rural** cohort expressed their loss of meaningful activities:
"*I am unable to collect firewood in the field, chop the wood and prepare fire to cook"*

“Cooking is very difficult but I try because I now use three legged pots on an open fire but with an electrical stove I struggle as the pots need to be held or balanced and as you can see this arm (lifted the weak hand up) is not working”

A woman in the **rural** cohort who did not have access to tap water said:
“I do not fetch water from the river anymore because I cannot lift the bucket up nor put and keep it on my head”

This old woman in the **rural** cohort felt that her cultural or traditional practice of mudding her floors with cow dung would no longer be practiced because she was no longer able to teach her daughters:
“*I cannot mud my floors with cow dung, who will teach my girls how to mud, I feel that this task will not be done anymore”*

A female participant in the **urban** cohort summarized her loss of home, family and community meaningful activities as follows:
“I cannot cook for my husband, clean my house, wash dishes, clothes, iron our clothes and sweep my yard. I cannot attend local funerals, church, weddings, parties and burial society or social club, it makes me feel sad”

A man in the **rural** cohort, who could not perform his community responsibility as expected by the community said:
“I am unable to go to the graveyard to assist with digging of the grave”
“I normally stay at the home of the people who are burying instead of going to the graveyard”

Though this patient in the **urban** cohort found it difficult to attend family gatherings, the family had come up with a solution to the problem so that the patient did not have to travel:
“I was no longer attending family gathering during Christmas but, the family asked to come to my house so I do not have to travel”

This young male participant in the **urban** cohort could not perform his youthful activities in his communities as he expressed it below:
“I am unable to play soccer with my friends or watch Kaiser Chief (his favourite professional soccer team) at the soccer stadiums”
“I cannot go to night clubs anymore”

Another male participant in the **rural** cohort expressed his inability to play soccer or coach young boys to play soccer as being frustrating, this was his passion, and he never stopped talking about soccer during his interview:
"I cannot train or coach young boys to play soccer anymore"

In speaking to the local people around his village, he was regarded as a soccer star.

From a leisure and recreation point of view, another old man in the **urban** cohort who played soccer in his area and still continued to play even in his old age, bragging about his soccer skills said the following:
"I used to play soccer, my soccer name was taxi driver because once the ball was passed onto me I would dribble through our opponents like a typical taxi driver and score a goal, but now I cannot play soccer anymore not even going to the stadium to watch it. Television is my last resort"

A woman in the **urban** cohort expressed her frustration at losing her meaningful activity of grooming herself in the following way:
"Things that I did before stroke like grooming myself especially going to the hair salon to do hair and nails and I am not able to do anymore"

Also from a leisure and recreation, point of view another participant from the **urban** cohort, who was an actor before the stroke said the following:
"I am in the showbiz, I am an actor and this was interrupted by a stroke"

Being a member of a church choir was one of the following **rural** cohort participant's hobbies but due to the stroke his voice had been affected, and he was not able to continue to participate in his church choir activities, though he still went to church:
"I used to sing in our church choir but not anymore because this stroke has affected my voice"

Another activity that was affected by stroke was people's ability to return to work. The inability to return to work affects the person's livelihood and existence. The theme below explores this further.

3.5.2.6 **Threat to livelihood (sustainable/productive livelihood)**

In the context of this study, threat to livelihood refers to unsustainable provision for the family or the inability to work. The subsequent result is of not being able to provide for the family; or

the inability to finish a training programme which would then enable one to get a job and earn a decent living.

One old woman from the **rural** cohort expressed her gratitude to the chief of the village who had provided food for her since her stroke but was not sure how long this food parcel provision would still continue thus threatening her existence:
"I would like to thank the chief of the village, he gives us food, but I do not know if he will still continue to provide this food parcel for us, so I need to sell vegetables in order to support my family"

From an education point of view, a young university student in the **urban** cohort group expressed his frustration as follows:
"There goes my career; I cannot go to school anymore, my parents paid the university and now I am unable to finish my degree. Who is going to support until I am old?"

Inability to return to work appeared to be more of a concern for the urban than rural participants, as expressed by the quote below from a man in the **urban** cohort.
"I have to go back to work because I need to pay rent for this (pointed at the room) room or else I would have to go back home in the Eastern Cape" (One of the rural provinces in South Africa).

Inability to drive as part of one's work was expressed by most participants as follows:
"I used to drive that was my work, I need to go back to work for my family"
Also an inability to take care of livestock as expressed by one man from the **rural** cohort:
"I want to be able to shepherd my cattles, so that my family may be fed"

As a result of being physically affected by the stroke most patients had lost hope in recovering from the stroke as can be seen below in the last theme.

3.5.2.7 **Loss of hope**

Feelings of helplessness, dissatisfaction and hopelessness were frequently expressed by most participants in **both settings**, with statements such as:
"I wish I could die than to be a burden to my children"

Some participants did not see the chance of their stroke healing or of them recovering to their usual level of activity:

"I don't think there is a cure for a stroke; does it mean I am going to live like this until I die?

A caregiver of a **rural** cohort participant expressed his loss of hope and sense of pity for his father in law as follows:
"Why must he continue to suffer like this, he is not able to talk, he sits in a wheelchair the whole day, he cannot do anything for himself, my poor mother in law must do everything for him, this is not fair"

Most participants in **both settings** drew on their spirituality and faith for hope as the following participant put it:
"I know God is there, he will heal me, and I believe in Him"

The following section discusses the results of this study.

3.6 DISCUSSION

This study set out to conceptualise community reintegration from the perspective of patients with stroke and their caregivers. An overwhelming picture of despondency was found, with few positive stories told in both the rural and urban settings.

3.6.1 Patient/Participants Characteristics

It is worth noting that the youngest person amongst the urban participants who had a stroke was 27 years old and in the rural cohort, the youngest person was 35 years old. Owolabi and Ogunniyi, (2009) in a Nigerian study had similar results in that their youngest participant was 30 years of age. Rhoda and Henry, (2003) and Hale et al., (1999) had their youngest patients at 33 and 44 years old respectively. These findings are different to the other studies conducted in developed countries, in an American study by Eaves, (2000); the mean age of the sample was 67 years and in a Canadian study by Mayo et al., (2002), the average age was 68, 4 years.

Although only one young patient revealed his Human Immunodeficiency Virus (HIV) positive status during the interview, it is worth commenting on the epidemiological changes of stroke due to HIV and Acquired Immunodeficiency Syndrome (AIDS) in this study. Due to the emergence of the HIV epidemic in South Africa, more young people are affected by conditions that were previously commonly seen in an older population like stroke (Connor et al, 2004, Mudzi, 2009). This may explain your younger age group, as many may not have disclosed their status.

3.6.2 Loss of Community Mobility or Restriction in Community Mobility

In this study, all patients in both settings expressed concerns regarding their reduced mobility within their homes and within the community. Walking is an important human activity which enables us to be productive and participative members of a community (Ada et al., 2009). The reduction in the ability to walk results in major limitations in community participation. Hill et al., (1997) found that many individuals after stroke could not walk fast enough to do their shopping. The consequence of poor walking ability is widespread and affects the entire family. Poor walking ability has been found to reduce the quality of life with reduction in participation in activities outside the home and therefore social isolation (Ada et al., 2009). The impression gained was not that they could not walk but were afraid to walk because of falling, slopes, terrain, slowing others up, difficulty negotiating furniture, embarrassed to be in public due to the way they were walking especially those who were using a walking aid.

In describing what life was like now, participants in both settings spoke at length about restrictions and losses of “taken for granted” freedoms and abilities. Participants were unable to move around their homes let alone in the community. They expressed feelings of frustration, de-motivation and discouragement. These feelings were shared by most participants in both settings albeit to varying degrees and in different environments as some participants found it difficult to move in their own homes whilst others found it difficult in the community. These findings are similar to feelings expressed by participants in a study by Pilkington, (1999). Thirteen participants who had mild to moderate stroke living in Toronto, Canada, between the ages of 40 to 90 years were interviewed on their experience of living with stroke. Participants in Pilkington’s study emphasized the importance of being independent, being able to move around and not have to depend on caregivers or aids/devices.

3.6.3 Social Isolation

Social isolation emerged as a prominent theme for participants in both settings. Participants expressed a sense of being cut off from the world as a result of their stroke and that their social relationships had deteriorated. The feeling of isolation made participants depend on other members of the family for activities of daily living and thus made them feel like they were a burden to everyone in the homestead.

Social isolation is defined through self report of knowing fewer people well enough to visit in their homes (Boden-Albala et al, 2005). Most people with stroke in this study stated that their restriction in mobility was the major cause of their social isolation. As the majority of stroke survivors must depend on others for everyday activities (Connor et al., 2004) social

relationships are critical to survival for patients after stroke and become of critical importance for their quality of life (Lynch et al, 2008).

Hale et al., (1999) reported that most participants in their study conducted in Soweto, South Africa had few people come to visit them at home. Garbusinski et al., (2005), found differing results in their study conducted in Gambia in that most participants participated in family life and resumed activities of daily living such as caring for children and attending family ceremonies. The authors attribute this to the social support and care that was given at home by the family members.

Glass et al., (1993) state that high levels of social support are associated with faster and more extensive recovery of functional status after stroke and thus social support may be an important prognostic factor in recovery from stroke (Glass et al., 1993). It may be that patients should be encouraged to socialize more so as to improve their recovery rate, to improve social relations and interactions with other people.

3.6.4 Loss of Role, Role Reversal and Loss of Personal Identity within the Family and Community

Most participants in both settings in this study felt that their roles have been reversed because the activities they used to do were now done by a member of the family. This loss of role and reversal of role in the family, and community seemed to reduce the significance and importance of the person with a stroke. The striking impact of stroke also involves the patient's role and social function. The social changes among others include that the patient has to depend on others for his/her basic personal and social needs (Hafsteinsdottir and Grypdonck, 1997). This dependence on others hugely changes the role of a person with stroke within his/her family and community.

Role changes are related to issues of dependence and social support. Social roles are altered when the patient can no longer work or dispense his/her responsibilities in a family and/or community. A shift in social roles challenges relationships that are already stressed by the newly dependant status of the patient (Lynch et al., 2008). In this study, all participants had a role to play as a mother, wife, father, sister in law, and a grandmother and these roles were fulfilled within the structure of a family or community. Many participants were also involved in the community at large e.g. local church leader or a preacher. Due to the stroke, many participants could not fulfil their role(s) fully.

3.6.5 Loss of Meaningful Activities of Daily Living

Participants in both cohorts expressed their loss of ability to undertake meaningful activities, when asked to explain their typical day or rather how they spend their day. Almost all participants said they did nothing all day other than watching television, just sitting or sleeping. When asked about their previous lifestyle it become very clear that these participants were not participating in activities they enjoyed.

Stroke is among the leading causes of long-term disability. Many people who have had a stroke live with physical, psychological and functional limitations that have an impact on their daily activities and social roles (Dombovy et al., 1987). A number of people with stroke will not be able to resume their previous activities (Parker et al., 1997). Their participation in daily living and social roles will therefore be restricted, leading to handicap situations in various aspects of their lives (Desrosiers et al., 2006b). The participants were not occupied during the day, these findings are similar to the ones found by Hale et al., (1999) on a similar cohort of patients.
Meaningful activities are normally determined by the importance of the task and whether the person was doing the task prior to his/her stroke e.g. female rural participants have to collect firewood to cook, it is therefore expected of them to do this task but due to the effects of stoke this important task is lost.

Driving a motor vehicle is essential to functional independence and community integration, as it enables access to work, shopping, health care and social activities (Griffen et al., 2009). Driving could also be part of a person's work. Stroke may affect this skill negatively and alternate transport such as public and private transport or relying on friends and family often does not adequately meet mobility needs of a person especially of a person who drove before the stroke. In the urban cohort there were 11 male participants, who indicated that they were driving before the stroke. For some, driving was done as part of their daily work as they were taxi drivers or a delivery person. It is this inability to drive as part of one's work that partly led to patients feeling that their livelihood was threatened. The threat to livelihood is discussed further, below.

3.6.6 Threat to Livelihood (Sustainable/Productive Livelihood)

The inability to return to work appeared to be more of a concern for the urban than rural participants. This could be due to the fact that most participants in the urban community were renting property and therefore had to pay rent at the end of the month or face eviction whereas in the rural communities most families own property so the pressure is less than that of participants in urban communities. Although all participants in this study had not returned to

work at the time of the interview most expressed the desire to return back to their paid occupations. Other participants expressed their desire to apply for government social grants (disability) since they were not able to return to their paid occupation.

The inability to return to work affects the person's livelihood and existence. Returning to work for people with stroke may contribute significantly to their life satisfaction, well being, self-worth and social identity, giving an opportunity to maintain independence as far as physically possible with the income generated through employment (Wolfenden and Grace, 2009). Pressures such as financial hardship (the lack of money to pay debts) may influence return to work. Return to work may be seen as an indication of recovery of patients with stroke. Garbusinski et al., (2005) in a study to describe the clinical outcome of stroke patients admitted to a tertiary hospital in Gambia, found that less than half of the participants in their study (n=162) were economically active before the stroke but had one year later resumed a paid activity i.e. had returned to their paid jobs.

The inability to drive as part of one's work was expressed by most participants especially most men in the urban cohort. Driving a motor vehicle is essential to functional independence and community integration, as it enables access to work, shopping, health care and social activities (Griffen et al., 2009). In this study, most participants expressed the desire to drive again following stroke especially those whose occupation was driving.

Lastly the inability to take care of livestock was viewed as being important mostly by the rural participants in this study in order to sustain family life in a rural setting. Most participants in this study had livestock in the form of cattle, sheep, goats, chickens and dogs. These livestock provided food for the family in the form of milk and meat as well as providing protection/security for the family. The participants felt that it was necessary for them to be able to take care of their livestock in order for the livestock to continue to provide for the family.

3.6.7 **Loss of Hope**

Participants felt that they were now going to be a burden to their spouses, children or family members; some even felt pity for their caregivers, whilst some felt that they are not going to ever recover from the stroke. The extreme case of loss of hope was expressed as wanting to die, by some participants. It is a common phenomenon for stroke survivors to express feelings of despair and helplessness after a stroke (Pilkington, 1999). The concept of hope can be characterized by expressions of uncertain feelings for the future. The feeling of hopelessness

is brought about by realising that they have acquired a new disability that they have to cope with for the rest of their lives.

The participants in both settings in this study expressed feelings of hopelessness and helplessness, especially being able to recover. On the contrary, participants in the Pilkington's study (1999) expressed feelings of hopefulness by using phrases like "getting back to normal" and "resuming everyday activities". In view of these hopes, participants in the Pilkington's study described their efforts and progress towards recovery. They considered making changes to adjust to the new disability in order to enhance their health and quality of life (Pilkington, 1999). In the researcher's opinion, the participants in this study focused more on the difficulties under the circumstances they faced by living in poor socioeconomic areas, therefore saw life in a very negative way, and were not able to cope, subsequently lost hope. Whereas participants in the Pilkington's study are from a developed country (Canada), where resources are available and accessible.

3.6.8 Summary of Study 1

3.6.8.1 Conceptualisation of community reintegration according to the context of participants in this study

The first objective of study 1 was to conceptualise community reintegration from the perspective of patients with a stroke and their caregivers within the context of rural and urban black South Africa. Collated, the seven themes emerging from these perspectives suggest a multidimensional conceptualisation of community reintegration. This conceptualisation thus incorporates the following: "*the ability to move around in one's home and community, of not being isolated, not having one's roles reversed or identity loss. The person should be able to work to sustain his/her life and not lose hope".*

Some similarities can be seen in the definition by Wood-Dauphinee et al., (1988: 583-590). Their definition started by defining integration as "*the organization of organic, psychological, and social traits and tendencies of an individual into a harmonious whole".* Therefore, "*reintegration to normal living could mean the reorganization of physical, psychological and social characteristics so that the individual can resume well-adjusted living after an incapacitating illness or trauma like stroke" (Wood-Dauphinee et al., 1988:* 583-590*).* Therefore, based on this definition and Study 1 findings, reintegration back into the community is the same no matter where you are, although the tasks and activities of daily living may differ

depending on the context for example rural versus urban areas, socioeconomic status and culture.

The same sentiment is shared by Trigg and Wood (2000: 288-99) in their definition of community or social reintegration "*as the ability of an individual to live in the most natural environment possible, interact with a wide variety of people, and take part in the usual activities of society".*

3.6.8.2 **Development of the preliminary outcome measure**

The second objective of this study was to develop a preliminary outcome measure that would be developed further in the subsequent studies of this thesis. Below is an account of how the themes emerging from this qualitative study informed the development of an outcome measure to assess community reintegration in the South African context.

3.6.8.3 **Item/statement generation per domain**

From the seven themes that emerged from this study 67 items were generated for the questionnaire using statements based on what the participants in both settings said in the interviews. These 67 items were categorised under 11 domains. The items were then phrased in the form of questions by the researcher for example "Since your stroke, are you able to?

The 11 domains were:

- activities of daily living (14 items),
- home responsibilities (14 items),
- family responsibilities (4 items),
- community responsibilities (11 items),
- religion (5 items),
- education (1 item),
- relationships (4 items),
- medical care (2 items),
- recreation (8 items),
- productivity (2 items),
- travel and transport (2 items).

All the domains identified were applicable to both settings but some items contained in the different domains were more applicable to one setting than to others. The domains identified in this study are almost similar to the domains identified in previous studies by Wood-Dauphinee et al., (1988), Willer et al, (1994), Trigg and Wood (1999), Van Brackel et al, (2006a) except for

inclusion of religion, travel and transport, and community responsibility. These domains were strongly identified by participants in both settings in this study as important factors affecting their community reintegration. The document produced from Study 1 was the preliminary outcome measure (see Appendix 3.13) which was validated in Study 2. The preliminary outcome measure was reviewed for wording, accuracy, clinical and non-clinical appropriateness by patients and caregivers who were involved in study 1 and rehabilitation professionals as part of the validation phase 1 in study 2. This process established further trustworthiness of the data collected in Study 1 (Guba, 1981).

3.7 CONCLUSION

An overwhelming picture of despondency was found, with few positive stories told in both settings. The themes identified from the interviews reflected the experience and issues that a patient with stroke has to deal with in a poor socioeconomic rural or urban area in South Africa. The themes identified in this study assisted in developing and generating items and domains used in the validation phases, Study 2.

CHAPTER 4

4. STUDY TWO: VALIDATION STUDY

PHASE ONE: VALIDATION OF THE PRELIMINARY OUTCOME MEASURE AND ITEM REDUCTION PROCESS USING EXPERTS AND PATIENTS.

4.1 INTRODUCTION

The objectives of this study were to establish the face and content validity of the preliminary framework of the outcome measure (OM) that was developed in study 1 and to determine the degree of consensus from experts and patients with regards to items to be included in the OM to assess community reintegration following stroke in a South Africa context (item reduction step 1). The preliminary OM was taken through a rigorous process of validation. This chapter will present the results of a Delphi technique study, conducted with a group of neurological rehabilitation and community based rehabilitation experts as well as the consultation with a psychologist and statistician. The results of a nominal group technique study with patients with stroke and their caregivers in both urban and rural settings (interviewed in the first study) will also be presented in this chapter.

4.2 METHODS

4.2.1 Study Design and Justification for using the Delphi Technique

The Delphi technique was used with a South African group of experts in community based rehabilitation and neurological rehabilitation. The Delphi technique is reported to be a useful research tool that can be used to obtain consensus from a chosen group. Gupta and Clarke (1996: 185-211) describe the primary purpose of the Delphi to be *"a method to obtain the most reliable consensus of opinion of a group of experts"*. The Delphi technique was chosen to obtain expert opinion because it allowed for wide consultation whilst eliminating geographical constraints (Gupta and Clarke, 1996). The purpose of a Delphi technique is to arrive at a consensus of professional opinion on a given topic, in this case, domains and items to include in this outcome measure to assess community reintegration after a stroke.

4.2.2 Delphi Technique Round 1 to 3

The objectives of these three Delphi rounds were:

- To establish face and content validity of the OM.

- To obtain consensus/agreement with regards to items to be included in the OM to assess community reintegration following stroke and to reduce the number of items on the preliminary OM.
- To develop the overall scoring system (per domain/item).
- To suggest a name for the OM.

4.2.3 Data Collection

4.2.3.1 Expert group sample:

The sample for this study was made up of a group of local (South African) neurological and community based rehabilitation experts, a psychologist and a statistician. The experts were physiotherapists and occupational therapists who had five or more years of clinical experience in neurological rehabilitation and/or community based rehabilitation. The psychologist, an expert in the development of outcome measures was consulted to assist with the psychometric properties of the OM. The statistician with a health statistics background assisted with the development and finalisation of a scoring system for the newly developed outcome measure.

4.2.4 Procedure

4.2.4.1 Delphi technique round 1

- The purpose of this round was to reduce the number of items, comment on the appropriateness of the items contained in the preliminary OM, and correct grammatical errors and ambiguity of the items.
- An information letter (See Appendix 4.2a) was sent via email to all the experts explaining the purpose and aim of the entire study and their specific input required for this process. The expert group was then asked to complete the consent form (See Appendix 4.2b) which also included their demographic information.
- In round one, two documents were sent via email to consenting participants. The first document contained the preliminary OM developed in study one with instructions for the experts (Document 1) and the second contained the definition and the components of community reintegration following stroke derived from the literature (Document 2) (See Appendices 4.3 and 4.4).
- The guidelines given to experts for completion of round one were as follows:
    1. “Please use document 2 (the one containing the definitions and components of community reintegration from the literature) to assist you when completing document 1” (Preliminary OM).
    2. In document 1, “please use the three point Likert scale provided to rate whether the item in your opinion appropriately measures community reintegration, namely “*must include, possibly include or exclude from the OM”.*

3. Please give your general and/or any specific comments about each item.

- The experts were given three weeks to respond to the questionnaire.
- If necessary, a follow up email to remind the experts about the submission date was sent a week after submission date.
- All non-responders were followed up via email by reminding them after the submission date.

4.2.4.2 **Delphi technique round 2**

- The purpose of this round was to continue with the item reduction process, comment on the appropriateness of the amended/corrected items, correct grammatical errors and any ambiguity of the items.
- In this round only one document was sent to all the experts with all the changes and amendments from round one, and including newly suggested items.
- All the items (28) that had **NOT** obtained 80% consensus from the experts in the first round and newly suggested items were sent back to all experts (See Appendix4.5 and 4.6).
- At this stage the experts were asked to make a final decision whether the remaining items needed to be included or excluded from the OM, therefore they were given a two point Likert scale namely "*include or exclude from the OM".*
- The expert had also to give general and specific comments on grammatical errors and ambiguity of these items.

4.2.4.3 **Delphi technique round 3**

- The purpose of this round was firstly to suggest a scoring system for all the items contained in the OM, comment on the appropriateness of the items in measuring community reintegration for patients with stroke in South Africa and lastly to suggest a name for this newly developed OM.
- In the third and last round, the third draft of the OM containing all the items with 80% and above consensus from round one and two with all grammatical and other suggestions taken into account was sent to all experts.
- In this round the experts were given the following guidelines in order to complete the task:
    1. Firstly suggest a scoring system for this outcome for all domains and items, bearing in mind the type of patients for which this OM was going to be used (for example mostly illiterate) and that this OM will be interview administered.
    2. Secondly, suggest a name for this newly developed OM.
    3. Lastly comment on whether you think this OM is really measuring community reintegration of Black patients with stroke in South Africa.

- At this stage, a psychologist who has experience in the development of OM was consulted to assist with the psychometric properties of the OM.
- A statistician, who has experience in health research, was consulted about the suggested scoring system.

4.3 NOMINAL GROUP TECHNIQUES

4.3.1 Study Design

A nominal group technique was used with patients with stroke and their caregivers.

4.3.2 The Rationale and Purpose of the Nominal Group Technique in this Study

The nominal group technique was chosen as the method for collecting data from the patients about this newly developed OM. The rational and purpose for providing this opportunity and soliciting input from the patients, was firstly, for patients to freely express themselves without them feeling overawed by the presence of the experts and because of the level of literacy amongst patients with stroke. Secondly, to give the patients an opportunity to give input on the content and construct of the OM in a more structured environment though less intimidating way. Lastly, the discussion in groups to arrive at a consensus is something that black SA people do when meeting about community issues.

4.3.3 Patients Sample

The sample was made up of the patients with stroke and their caregivers who took part in study one from both the rural and the urban settings. The patients were randomly selected from the data list of study one.

4.3.4 Procedure:

- The **first** meeting was conducted at a PHC clinic (in both the rural and urban areas) to check for difficult, culturally appropriate and ambiguous items from the patient's perspective.
- The researcher explained the purpose of the meeting and permission to participate in this second study was sought from patients as well as their caregivers (See Appendix 4.1a and 4.1b).
- The researcher facilitated the meeting by reading and explaining each item per domain contained in the preliminary OM (See Appendix 4.8) and patients had to respond to the following questions:
  - Is the item clear and understandable?
  - Is the item important for their community reintegration?

- Is the item culturally and contextually appropriate?

- The patients were also allowed to discuss any issue arising from the items and other participants in this meeting.
- A research assistant made notes of the suggested corrections and recommendations per item per domain.
- The patients were given an opportunity to make any further corrections to the document after the research assistant had read the items in the language that the patients were comfortable with, according to the corrections and recommendation suggested in the meeting.
- The **second meeting** was with the second draft of the OM after it had been altered based on the combined input of the experts (Delphi round one and two) and the patients (meeting 1) (See appendix 4.9).

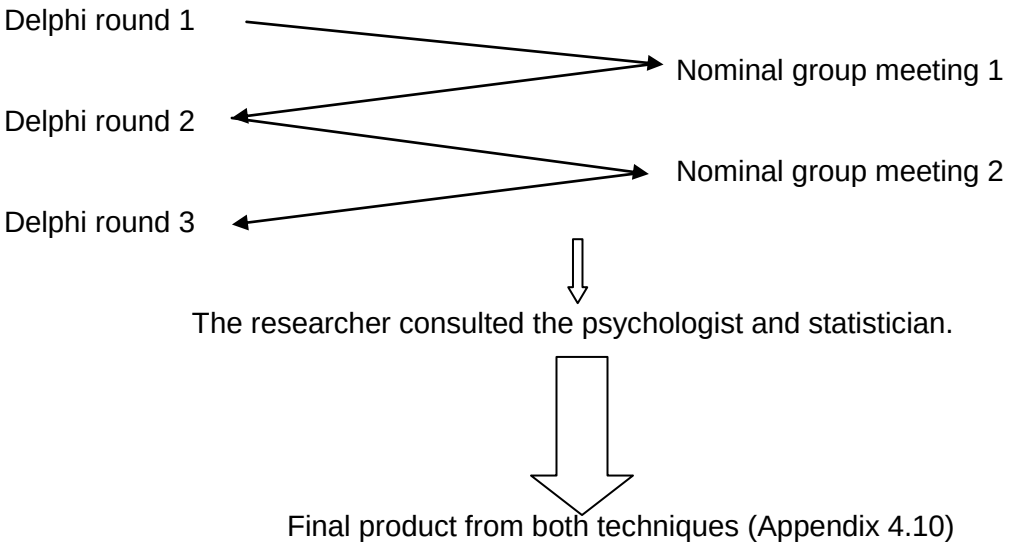


Figure 4.1: A Diagrammatic Illustration Showing how the Information from the Two Techniques was used to Inform the Next Stage

4.4 ANALYSIS

There are no statistical tests to analyse face and content validity. The new OM had to cover the domains that constitute community reintegration as defined by patients and caregivers, the literature and experts. No references could be found to determine what a standard level of consensus is. In this study the level of consensus was determined by using percentages of responses from the experts who agreed that an item be included or not. The level of consensus was targeted at 80% (Green et al., 1999; Deane et al., 2003). Three rounds of the Delphi technique were used to ensure consensus was reached and also the responses (feedback) received through a series of rounds (three) are more reliable indicators of

consensus (Crisp et al., 1997). For the nominal group technique, patients' consensus was determined after agreement was reached by all participants for each item before proceeding to the next one.

4.5 RESULTS

4.5.1 Results of the Three Rounds of Delphi Technique with Experts

Ten experts were contacted via email. A hundred percent response rate was reached in all the three rounds of the Delphi Technique. The table below shows the characteristics of the experts involved in the Delphi technique.

Table 4.1: Characteristics of Experts who Participated in Delphi Technique (Characteristic of Participants (n=10))

Gender:	All female
Qualifications and profession:	M Sc (Physiotherapy PT): 3 M Sc (Occupational Therapy OT): 1 M Sc (Rehabilitation): 1 MPH: (1 OT and 1 PT): 2 PhD (All PT): 3
Area of speciality/interest:	Community Based Rehabilitation: 4 Neurological Rehabilitation: 6
Years of working in the area:	Mean years: 14,5 years, range 13-36 years
Sector of work:	Academic: 4 Clinical: 4 Other: 2
Provinces in South Africa where the experts reside and work:	Mpumalanga province: 1 Gauteng province: 6 Limpopo province: 1 Western Cape province: 2

4.5.2 Results of the Delphi Technique Round 1

Due to the excess number of tables of results in this section of this chapter only tables with 80-100% consensus will be presented here. The remainder of the tables have been placed in Appendix 4.5 but they have been commented on in the body of the results.

1. ACTIVITIES OF DAILY LIVING AND PERSONAL CARE (8/18 items)

The first domain had 18 items and out of the 18, eight reached 80% and above consensus by the experts for inclusion into the OM. The table below illustrates items which obtained 80% and above consensus.

Table 4.2 below indicates the items to be included in this domain.

Table 4.2: Items to be Included Under Domain 1

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
1.1 Are you able to get up and out of bed in the morning?	10/10	100%	None
1.4 Are you able to wash yourself?	10/10	100%	None
1.5 Are you able to dress yourself?	10/10	100%	None
1.6 Are you able to feed yourself?	10/10	100%	None
1.7 Are you able to drink from a cup or glass?	8/10	80%	None
1.9 Are you able to carry a heavy object for example shopping bags (two-three maximum)?	8/10	80%	Put in home and family responsibility domain 2.
1.10 Are you able to move around in small spaces? b) Are you able to move in uneven/hilly areas?	9/10	90%	The word “walk” has been replaced with “move” around to include those who are wheelchair bound, the word “small” replaced the word “confined spaces”
1.11 Are you able to walk in your a) home, b) yard c) community?	9/10	90%	Replace the word “walk” with “move”.

Table 4.3 indicates the items where consensus was not reached (see Appendix 4.5).

Table 4.4 indicates the item that was suggested to be added to the list of items under domain 1 (see Appendix 4.5).

2. **HOME AND FAMILY RESPONSIBILITIES (5/18 items)**

Domain 2 also had 18 items, only 5 of these items achieved 80% and above consensus. Table 4.5 below indicates these items which should be included in the OM under this domain.

Table 4.5: Items to be Included Under Domain 2

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
2.1 Are you able to clean your house?	9/10	90%	Combine with 2.2, require similar functional ability.
2.4 Are you able to cook and prepare meals for your family?	9/10	90%	Combine with 2.5, and ask participants if it is applicable.
2.6 Are you able to clean the area and utensils used for preparing meals?	8/10	80%	None
2.7 Are you able to wash the clothes?	9/10	90%	None
2.15 Are you able to collect water from the river/communal tap?	8/10	80%	Exclude or include in the above item and only if it is or was the patient's main role.

Consensus was not reached on the items indicated in Table 4.6 (see Appendix 4.5).

3. **COMMUNITY AND SOCIAL RESPONSIBILITIES (2/6 items)**

Domain 3 had 6 items and only 2 reached 80% and above consensus. Table 4.7 below indicates these items.

Table 4.7: Item to be Included in Domain 3

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
3.1 Are you able to attend social events in your community such as funerals, parties or weddings?	10/10	100%	None
3.2 Are you able to attend burial society, social clubs meetings and other community structures meeting or meetings called by the chief/councillor in your community?	8/10	80%	Could combine with 3.1, it is covered there.

Consensus was not reached on the items indicated in Table 4.8 (see Appendix 4.5).

4. **RELIGION (1/2 items)**

Domain 4 had 2 items, only 1 item achieved 80% consensus. Table 4.9 below indicates the item to be included in this domain.

Table 4.9: Item to be Included in Domain 4

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
4.1 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?	8/10	80%	Need to be more holistic so that all religious categories are covered by using the word “religion” as it covers all.

Consensus was not reached on the other items indicated in Table 4.10 (see Appendix 4.5).

5. **RELATIONSHIPS (4/8 items)**

Domain 5 had 8 items, and only 4 items reached 80% and above consensus. Table 4.11 below indicates these items.

Table 4.11: Items to be Included in Domain 5

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
5.1 Are you able to be intimate with your spouse/partner?	9/10	90%	None
5.2 Are you able to interact and relate generally to people?	8/10	80%	Delete “of the same/opposite sex” Or add “potential love partner”?
5.4 Are you worried about your appearance when out in the public?	9/10	90%	Should it go under personal care? Too negative and emotional, suggestion “ Are you able to make sure you look presentable when you go out in the public” Does this stop you from going out?
5.6 Are you able to communicate with your family members? b) Or people in your area?	9/10	90%	From domain 1.

Consensus was not reached on the other 4 items and they are described in Table 4.12 (see Appendix 4.5).

Table 4.13 indicates the items that were suggested to be included in domain 5 (see Appendix 4.5).

6. **TRAVEL/TRANSPORT (3/5 items)**

Domain 6 had 5 items, only 3 had 80% and above consensus, these are shown in Table 4.14 below.

Table 4.14: Items to be Included in Domain 6

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
6.1 Are you able to get to the clinic/hospital to collect your medication or for rehabilitation/nursing/ medical help?	10/10	100%	None
6.3 Are you able to get into a taxi or car or bus or train or donkey cart?	10/10	100%	Too many options!
6.4 Are you able to get to the clinic/hospital for rehabilitation/medical or nursing help?	9/10	90%	Combine with 7.1.

Consensus was not reached on the other 5 items, indicated in Table 4.15 (see Appendix 4.5).

Table 4.16 shows the item suggested to be included into domain 6 (see Appendix 4.5).

7. **RECREATION AND LEISURE (1/4 items)**

Domain 7 had 4 items, only 1 reached 90% consensus and Table 4.17 below shows this item.

Table 4.17: Item to be Included in Domain 7

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
7.4 Are you able to get out of the house to go shopping in town or going out with friends or watch a soccer match at a stadium?	9/10	90%	Covered in the previous domain.

Consensus of 80% or over was not reached on the other 3 items indicated in Table 4.18 (see Appendix 4.5).

The two domains below were separate in the first draft of the preliminary OM. Domain eight titled “Productivity” had three items and domain nine titled “Education” had two items. The experts suggested that these two domains should be combined into one domain (eight) and be titled “Work and Education”. The results of this suggestion will be presented in the second round results of the Delphi technique.

8. **PRODUCTIVITY (1/3 item):**

Table 4.19 below indicates the only item the experts agree should be included in this domain.

Table 4.19: Items to be Included in Domain 8

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
8.1 Are you working or intending to return to work? Are you able to go back to work?	10/10	100%	Reword this item: “Are you able to go back to work? Do not include the word “intend to return” as they could intend to go back to work forever.

Consensus was not reached on the other items and these can be seen in table 4.20 (see Appendix 4.5).

9. **EDUCATION (0/2 items):**

None of the items in this domain reached a level of consensus amongst the experts to be included in the OM. The excluded items can be seen in Table 4.21 (see Appendix 4.5).

Summary of Delphi technique round 1:

A total of 25 out of 60 items reaching a consensus of over 80% and thus were included in the OM at the end of round one. Two new items were suggested to be added.

4.5.3 Results of the Delphi Technique Round 2

Due to the excess number of tables of results in this section of this chapter only tables with 80-100% consensus will be presented here. The remainder of the tables have been placed in appendix 4.7.

In this round a total of 28 items were sent back to all experts to make a final decision as to the `inclusion or exclusion of these items. These 28 items included the ones that had less than 80% consensus and those that were suggested to be added to the OM from round one. The results of the second Delphi round are presented below.

1. ACTIVITIES OF DAILY LIVING AND PERSONAL CARE

Table 4.22 below indicates the items to be included in this domain.

Table 4.22: Items to be Included

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
1.2 Are you able to pour water into a kettle/basin?	9/10	90%	None
1.8 Are you able to write or draw a cross?	10/10	100%	None
1.17a) Are you hopeful that you will get better?	8/10	80%	Is this measuring community participation or depression/emotional related question? Put this under a different heading e.g. psychological adjustment/coping. This is not an activity or personal care item.

Table 4.23 indicates the items to be excluded in this domain (see Appendix 4.7).

2. HOME AND FAMILY RESPONSIBILITIES:

Table 4.24 below indicates the items to be included in this domain.

Table 4.24: Items to be Included

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
2.2 Are you able to clean your yard i.e. sweep, pick up papers, mud the floors with cow dung?	9/10	90%	None
2.3 Are you able to work in your garden or fields?	9/10	90%	None
2.8 Are you able to hang the clothes on a washing line?	9/10	90%	Some people put their clothes on the ground to dry, not necessary to be able to hang clothes.
2.11 Are you able to take care of your livestock (if you have or do you have livestock) e.g. feed your dogs or herd/tend your cattle/ goats, including milking?	9/10	90%	Shepherd is for sheep, herd or tend is inclusive of all animals
2.13 Are you able to collect firewood, chop and prepare fire?	9/10	90%	None
2.17 Are you able to teach children home keeping tasks e.g. cultural/traditional cooking, and mudding with cow dung?	8/10	80%	Included in 2.18

Table 4.25 indicates the items to be excluded in this domain (see Appendix 4.7).

3. **COMMUNITY AND SOCIAL RESPONSIBILITIES:**

Table 4.26 below indicates the item to be included in this domain.

Table 4.26: Item to be included

Item	Number of response (n)	Level of consensus /agreement (%)	Comment
3.3 Are you able to carry out your community roles e.g. Singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregates,?	10/10	100%	These things are very important in the rural community. Just change the order of your examples, putting the more common ones first e.g. singing in the choir before preaching. You could also make into 2 questions.

5. **RELATIONSHIPS**

Table 4.27 below indicates the items to be included in this domain.

Table 4.27: Items to be Included

Item	Number of response (n)	Level of consensus /agreement (%)	Comment
5.3 Are you able to physically assist other people e.g. help someone get up, help someone with poor balance?	8/10	80%	Give some examples (help someone get up, help someone with poor balance, walk...)
5.5 Are you able to accept help and support, including emotional support from family and friends?	9/10	90%	I think you are getting into complex waters here! Is this measuring community reintegration?
5.7 Are you able to solve problems with family and friends?	9/10	90%	I think you are getting into complex waters here! Is this really measuring community reintegration?
5.8 Do you have friends and family who visit you at home?	9/10	90%	How is this outcome a measure of community reintegration? Phrase it like other items.

6. TRAVEL/TRANSPORT

Table 4.28 below indicates the items to be included in this domain.

Table 4.28: Items to be Included

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
6.2 Are you able to drive?	9/10	90%	It depends on the population you use your questionnaire on. Many rural women don't drive. Otherwise change into 2 questions: a) Were you able to drive before b) if yes are you able to drive now? This is too limiting I would imagine many women in the rural areas have never driven. Add: Or use of public transport Phrase it this way: "Are you able to use the transport you used before the stroke or other forms of transport independently"?
6.5 Are your friends and family assisting you with your travelling needs?	10/10	100%	Very important item, especially for patient who are not working or getting a grant. Just need to phrase it like the other items.

7. RECREATION AND LEISURE

Table 2.9 below indicates the items to be included in this domain following the second round of the Delphi.

Table 4.29: Items to Include

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
7.1 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?	10/10	100%	Change it to 2 questions, many are illiterate. In rural SA there are many people to whom reading isn't really important, though.
7.4 Are you able to do a physical activity such as playing any sport?	9/10	90%	Change the wording to "are you able to play sport?" also asks if they were able to do so before. Just so rare in rural areas for older folks, and indeed for the younger age groups who may have a stroke.

8. WORK AND EDUCATION

Table 4.30 below indicates the item to be included in this domain.

Table 4.30: Item to be included

Item	Number of response (n)	Level of consensus/ agreement (%)	Comment
8.1 Are you able to attend school or training programmes in or out of your community? "Adult education included"	8/10	80%	None

Table 4.31 indicates the item to be excluded in this domain (see Appendix 4.7).

Summary of Delphi Technique Round 2

Nineteen out of 28 of the items sent back to the experts in round two were included in the OM and the final number of items to be included in the OM after the first two rounds was 44/60.

4.5.4 Results of Delphi Technique Round 3

4.5.4.1 Suggested overall and domain scoring system for the OM

Some experts were very general in their suggestions whilst others were more specific regardless of the instructions given in the email sent to all participants. Each of the 10 experts suggested the following as scoring systems:

Expert 1: Yes/No or two stage response. Keep it simple.

Expert 2: 3-Yes (independently), 2- Yes with help (verbal cueing, supervision), 1- Yes with major help (physical help of 1 or 2, verbal direction)

Expert 3: 3- Yes, 2- Able with minor help, 1- Yes with major help, 0- No

Expert 4: 3- Yes, 2- Able with minor help, 1- Yes with major help, 0- No, N/A in certain items

Expert 5: Four point Likert scale with some sort of choices like: Hardly ever, Sometimes, Most of the time, Always

Expert 6: Alone/with help or sometimes/not at all **OR** easily, with difficulty, not at all

Expert 7: 1- Never, 2- Rarely, 3- Sometimes, 4- Often, 5- Always

Expert 8: For the first 3 sections: 5= cannot do at all, 4= with the physical help of 2 or more people, 3= with the physical help of 1 person, 2= with light support (can be via verbal support/ i.e. with words only) of someone, 1= independent, but with some help of an aid e.g. crutch, 0= completely independent
For the rest of the sections, I think a YES OR NO option, with an explanatory notes for when the answer is NO.

Expert 9:

1 = Completes 100% of the task alone effectively and efficiently
2 = Completes 100% of the task alone with difficulty and slowly
3 = Completes 75% of the task unassisted-caregiver present occasionally to give minor assistance with a few aspects of task

4 = Completes 50% of the task unassisted-caregiver present most of the time to give assistance with half the task

5 = Completes 25% of the task unassisted-caregiver present constantly and gives moderate assistance with most aspects of the task

6 = Completes none of the task unassisted-caregiver present constantly and gives complete assistance with task

Expert 10:

3- Able with no help, 2- Able with minor help, 1- Yes with major help, 0- No

OR

Another option of Likert scale is to ask the participants to mark on a community integration index where their response approximately is:

0 1 2 3 4 5 6 7 8 9 10

Cut off points:

a) 80% and above means full reintegration
b) 79%-61% moderate reintegration
c) 59%-41% minimal reintegration
d) 40%-0% no reintegration

OR

I recommend a 3 point Likert scale with a response like:

Can do completely without assistance

Requires assistance

Unable to do at all

4.5.4.2 **Suggest a name for this newly developed outcome measure (OM):**

The following were suggested as names for the newly developed outcome measure by the 10 experts:

Expert 1: The Community Reintegration Scale for Stroke Survivors (CRSSS)

Expert 2: Stroke Rural Integration Measure (SRIM)

Expert 3: Maleka Stroke Community Reintegration Measure (MSCRIM)

Expert 4: The South African Stroke Community Reintegration Measure (SASCRM)

Expert 5: Douglas post stroke community integration scale (DPCIS) **OR** post stroke community integration scale (PSCIS)

Expert 6: South African Stroke Functional Independence and Community Integration Index/Scale (SASFICI) **OR** South African Stroke Index (SASI)

Expert 7: Community Reintegration South African Stroke Measure (CRISSM) **OR** South African Community integration Stroke Measure (SCISM)

Expert 8: Activity, Participation and Reintegration Stroke Questionnaire SA version (APR Stroke questionnaire)

Expert 9: South African Post Stroke Community Reintegration Outcome Measure (SAPSCROM)

Expert 10: South African Community Reintegration tool (SACRT) **OR** South African Stroke Reintegration Tool (SASRT)

4.5.4.3 **Comment on whether you think this OM is really measuring community reintegration of patients with stroke in a South African context:**

The experts were asked to comment on the appropriateness of the OM, below are their comments:

Expert 1: *"I think so but you would need to examine the validity (criterion and construct validity) to answer this question with certainty".*

Expert 2: "*Yes, but still need to take it through the rigorous process to test its validity and reliability".*

Expert 3: "*Yes the tool does measure community reintegration in a South African context (rural and urban)- it can also be used in other developing countries with a similar setting to South Africa-actually your post doctoral can be testing it in one or two other SADEC countries and beyond-that is where the collaboration will start".*

Expert 4: "*Yes, I agree, I think it does measure community reintegration in SA context.. you would probably find it could later be extended to other acquired pathologies, to not just stroke…lots of post-graduate and collaboration opportunities".*

Expert 5: "*I do think it will measure outcomes post stroke".*

Expert 6: "*This outcome measure does measure community re-integration following stroke in a Southern African context".*

Expert 7: "*I think it has aspects that are applicable across the globe and aspects that are peculiar to African and aspects that are definitely South African so in all yes".*

Expert 8: "*Yes, I think it definitely includes more aspects/domains applicable to the stroke survivors in the SA context".*

Expert 9: "*Still concerned that the following items* (listed in the tables in the results section) *do not really affect community reintegration unless you define adequate personal and home management as part of this. It does reflect the aspects to look at for assessment of stroke patients".*

Expert 10: "*Yes it does, yes, I think it measures participation largely in the residential and somewhat community".*

4.5.4 Results of Nominal Group Technique with Patients

A total of 10 patients were recruited for the nominal group technique. The meetings lasted about one to two hours.

The table below show the characteristics of the patients who were involved in the nominal group technique.

Table 4.32: Characteristic of the Participants in the Nominal Group Technique

Characteristic of Participants		Values (n=10)
Age	:	Mean age= 52 years, range 35-65 years
Gender	:	Six females and four males
Marital status	:	Married, widow, divorced, separate, single
Access to caregiver	:	All had caregivers
Education obtained	:	Ranging from grade 0 to grade 6
Side of Hemiplegia	:	Four left and six right
Date of Stroke	:	Ranged from 2001-2007
Employment status	:	All unemployed, previously: house maid, gardener, motor mechanic
Location of the interview	:	PHC clinics and patients homes
Urban vs. Rural	:	Urban: 5 Rural: 5

4.5.4.1 **Results of the nominal group technique meeting 1**

Due to the excess number of tables of results in this section of this chapter only one table will be presented here. The remainder of the tables have been placed in appendix 4.8.

Table 4.33 below shows the responses to the three questions asked of participants from both rural and urban cohort in domain one (activities of daily living and personal care).

DOMAIN 1: ACTIVITIES OF DAILY AND PERSONAL CARE (17 items)

Table 4.33: Nominal Group Meeting 1, Domain 1

Item	Is the item clear and understandable?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
1.1 Are you able to get up and out of bed in the morning?	Yes	Yes	Yes	None
1.2 Are you able to pour water into a kettle?	Yes	Yes	Yes	None
1.3 Are you able to pour water into the basin?	Yes	Yes	Yes	**Urban:** patients in this urban group use a bath to wash. **Rural:** patients felt this was a necessary activity/task as most use a basin to wash.
1.4 Are you able to wash yourself?	Yes	Yes	Yes	None
1.5 Are you able to dress yourself?	Yes	Yes	Yes	None
1.6 Are you able to feed yourself?	Yes	Yes	Yes	None
1.7 Are you able to drink from a cup or glass?	Yes	Yes	Yes	None
1.8 Are you able to use your hand to write?	Yes	Yes	Yes	**Urban:** Some patients in the cohort group can't write, but draw a cross to sign a legal document. **Rural:** All rural cohort could not read nor write, therefore drawing a cross is more appropriate because that is what they get asked to do
1.9 Are you able to carry a heavy object for example shopping bags?	Yes	Yes	Yes	**Both urban and rural:** Depends on the weight of items bought, 1-3 maximum shopping bags.
1.10 Are you able to walk in confined spaces and uneven/hilly areas?	Yes	Yes: urban May include for rural	Yes	**Urban:** Especially the type of houses we live in, we tend to lose balance **Rural:** Not much of a challenge because their houses are big enough.
1.11 Are you able to take a walk in your home, yard or community?	Yes	Yes	Yes	None
1.12 Are you able to go to the hair salon or barber shop for grooming yourself?	Yes	No	Yes	Not important for community reintegration
1.13 Are you able to do the exercises you were shown by your therapist at home?	Yes	Yes	Yes	None
1.14 Are you able to converse with your family members or people in your area?	Yes	Yes	Yes	None

Table 4.33: Continued

1.15 Are you able to remember things told and events easily?	Yes	Yes	Yes	**The urban cohort** complained of loss of memory and forgetfulness more than the rural cohort.
1.16 Are you able to make decisions regarding your life and family issues?	Yes	Yes	Yes	None
1.17 Are hopeful/hopeless that you will/will not get better?	No	Yes	Yes	**Both urban and rural:** A bit confusing to have both words in one sentence.

The following tables have been placed in Appendix 4.8:

- Table 4.34 indicates the responses to the second domain (home and family responsibility).
- Table 4.35 indicates the responses of the patients to domain three (community and social responsibility).
- Table 3.36 indicates the responses of patient to domain four (religion).
- Table 4.37 indicates the responses of the patients to domain five (education).
- Table 4.38 indicates the responses of patients to domain six (relationships).
- Table 4.39 indicates the responses of patients to domain seven (travel/transport).
- Table 4.40 indicates the responses of patients to domain eight (recreation and leisure).
- Table 4.41 indicates the responses of patients to domain nine (productivity).

The results of the second nominal technique group meeting are presented below.

4.5.4.2 Results of Nominal Group Technique Meeting 2

Due to the excess number of tables of results in this section of this chapter only one table will be presented here. The remainder of the tables have been placed in appendix 4.9.

Patients were in agreement with most items in the OM. Table 4.42 below indicate the responses of patients to domain one (activities of daily living and personal care).

DOMAIN 1: ACTIVITIES OF DAILY LIVING AND PERSONAL CARE (9 items)

Table 4.42: Nominal Group Meeting 2, Domain 1

Item	Question clear?	Important for Community reintegration?	Appropriateness culturally and contextually?	Comments
1.1 Are you able to get up and out of bed in the morning?	Yes	Yes	Yes	None
1.2 Are you able to pour water into a kettle/basin?	Yes	Yes	Yes	None
1.3 Are you able to wash yourself?	Yes	Yes	Yes	None
1.4 Are you able to dress yourself?	Yes	Yes	Yes	None
1.5 Are you able to feed yourself?	Yes	Yes	Yes	None
1.6 Are you able to drink from a cup or glass?	Yes	Yes	Yes	None
1.7 Are you able to write or draw a cross?	Yes	Yes	Yes	None
1.8) Are you able to move around uneven/hilly areas?	Yes	Yes	Yes	None
1.9 Are you able to move around in your?	Yes	Yes	Yes	None
a) Home,				
b) Yard				
c) Community?				

The following tables have been placed in Appendix 4.9:

- Table 4.43 indicates the responses of patients to domain two (home and family responsibilities).
- Table 4.44 indicates the responses of patients to domain three (community and social responsibilities).
- Table 4.45 indicates the responses of patients to domain four (relationship).
- Table 4.46 indicates the responses of patients to domain five (travel and transport).
- Table 4.47 indicates the responses of patients to domain six (recreation and leisure).
- Table 4.48 indicates the responses of patients to domain seven (work and education).
- Table 4.49 indicates the responses of patients to domain eight (psychological adjustment/coping).

4.6 CONSULTATION WITH THE PSYCHOLOGIST AND STATISTICIAN

The purpose of this consultation was to seek advice on how to investigate the psychometric properties of this newly developed OM. The psychologist and statistician who were consulted are regarded as experts in development of outcome measures in South Africa.

The following were the psychologist's and the statistician's suggestions:

- To conduct factor analysis on the OM to further reduce the items and group factors accordingly (next step in the item reduction process).
- Do not use dichotomous responses in the OM, as dichotomous responses are difficult to use and analyse in factor analysis.
- Domain 4 (Relationship), the responses were dichotomous, and according to Comrey, (1978) this can lead to anomalous results, due to firstly the difficulty in analysis when using dichotomous responses and secondly dichotomous responses lead to a loss of efficiency of instrument, and a reduction in its correlation to other measures (Streiner and Norman, 2003). It was suggested the items should rather be changed to asking about patient's satisfaction with relationship to self, others and community. In that case, a three point Likert scale response was suggested and adopted namely:
  - Not satisfied (0)
  - Satisfied (1)
  - Very satisfied (2)
- The items in domain four (relationship) were thus rephrased as follows:

Since your stroke, please rate your satisfaction with how you relate to yourself and others on a scale of 0-2:

Table 4.50: Changed Items

Item	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)
4.1 How satisfied are you with your intimacy with spouse?			
4.2 How satisfied are you with your interaction with other people?			
4.3 How satisfied are you with your appearance in public?			
4.4 How satisfied are you with your communication with family?			
4.5 How satisfied are you with your communication with people around you?			
4.6 How satisfied are you with your visitors?			
4.7 How satisfied are you with help and support that you receive from your family and friends?			
4.8 How satisfied are you with your ability to solve family and friend's problems			
4.9 How satisfied are you with your ability to physically assist someone?			

- Domain eight (Psychological adjustment/coping) responses were also dichotomous; therefore the following was suggested to make the response more specific but the items were kept the same.

  Item one
  - Not at all (0)
  - Somewhat (1)
  - Definitely (2)

  Item two and three of domain eight were scored as follows:
  - Not at all (0)
  - To some extent (1)
  - To a full extent (2)
- An assessor would need to total the score from the different domains so as to be able to calculate the overall score for the patient. At this stage, the overall score for this outcome measure was not finalised because factor analysis was still going to be conducted.
- The last suggestion given was that the assessor would need to indicate whether the score was for baseline or follow up assessment, therefore they suggested this be added to the instructions for the assessors.

The final product (the newly developed outcome measure) from study 4 can be found in Appendix 4.10

4.7 DISCUSSION

4.7.1 The Expert's and Patient's Demographics Characteristics

The use of the Delphi as a technique to solicit input from people with expertise in physiotherapy is growing (Hale and Eales, 2001; Cook et al., 2006; Raine, 2006; Myezwa, 2009; Roberts, 2009; Rushton and Moore, 2009). A number of rehabilitation professionals were consulted to be part of this study as to the content, wording, appropriateness and suitability of items included in the OM. The same professionals also assisted them with item reduction of the OM. The professionals who were consulted were physiotherapists and occupational therapists who are either community based therapist and/or neurological rehabilitation experts.

In this study the expert's experience was indicated by the number of years spent in the area of speciality and by qualifications. The years of experience of experts ranged from 13 to 36 years. All the experts had post graduate degrees in their area of speciality as indicated in the results

section. In a study by Robert's (2009) similar criteria to obtain consensus among physiotherapists in the UK on the use of normal saline instillation prior to endotracheal suction were used. The physiotherapists in Roberts' (2009) study were senior or superintendent physiotherapists who had years of experience in an intensive care unit. Inclusion of experienced people assists in making sure that all issues that are being researched are considered and adequately debated before a decision is made.

With regards to the nominal group technique, normally experts are used (Potter et al, 2003a; Jackson et al, 2009; Rushton and Moore, 2009) but one can argue that people who are affected by the issue are in themselves experts (Fink et al., 1984; Potter et al, 2003b). The patients who were interviewed in Study 1 were included for this purpose. Their demographic information was similar to patients in Study 1. The highest level of formal education obtained by this cohort was to the primary level only, illustrating that this sample were not well educated and would not have been able to partake in a Delphi Technique which required a fairly high skill of literacy. The verbal format of the nominal group technique was therefore more appropriate to use under these circumstances. In addition, the discussion in groups to arrive at a consensus is something that black SA people do when meeting about community issues.

4.7.2 Delphi Technique Rounds and Nominal Group Meetings

As can be seen in Figure 1, the two processes informed each other with the intention of producing an OM that balanced the views and perspective of the rehabilitation experts, patients and caregivers. There was an agreement between experts and the patients with regards to what community reintegration entails based on the results obtained from these two techniques.

Delphi round 1 and nominal group technique meeting 1

At the end of the Delphi technique round one, a total of 25 out of 60 items were included. The experts were concerned about the clarity (ambiguity) and content of the items contained in the OM. They were also concerned about the length and the time it would take to administer this OM, therefore items that sounded similar were combined and merged to reduce repetition and duplication of items. In the same way some domains were also combined, for example the "Productivity" and "Education" domains were combined into one domain namely "Work and education".

The patients on the other hand were more concerned with the way the item affected their community reintegration, therefore the inclusion of an item was based on whether they thought

the item was important. In most of the domains both the urban and rural cohorts agreed on inclusion of most items except for domain two (Home and family responsibilities), because some of the items are very gender specific. This was more of an issue for the rural cohort than the urban cohort. Trigg and Wood (1999) used the same approach to solicit patient input in the development of SIPSO but instead used a postal survey and not face to face meetings as their participants were literate.

Delphi round 2 and nominal group technique meeting 2

Nineteen out of 28 of the items sent back to the experts in round two were included in the OM and the final number of items to be included in the OM after this round and round one was 44/60. Domain nine was suggested to be included in the OM in order to put all items that have psychological and emotional adjustment together.

The nine items that were finally excluded were from:

- Domain one (Activities of daily living and personal care), because the experts and patients felt that they were covered in other items (item 1.12) and that some do not really measure community reintegration (item 1.13) or the item has been phrased negatively (item 1.17 b).
- Domain two (Home and family responsibilities), because the experts and patients felt that they were more gender specific (items 2.9, 2.10, 2.14, 2.16 and 2.18). Item 2.14 was viewed as part of cleaning and item 2.16 both patients and experts felt that the task was not applicable anymore to either setting (rural or urban). Some for example 2.18 had unrelated examples thus likely to cause confusion with patients.
- Domain eight (Work and education), item 8.2 was excluded because volunteer work is similar to all the other types of occupation. The suggestion was to include it with item 8.1 as an example.

Delphi round 3

In this round, the experts suggested scoring systems for the OM and this will be discussed later in this section.

In addition, the experts had to suggest a name of this newly developed OM. The suggested names reflect three main points; firstly, the origin (that it was developed in South Africa), secondly for whom and why it was designed i.e. patients with stroke to assess their community reintegration and lastly who designed the OM, to brand the OM. The naming of the OM was not finalised as one expert suggested it should be delayed until the whole item reduction process was complete.

The experts had also to comment on the appropriateness of the OM within a South African context. As can be seen in their responses below, all felt that the items contained in the OM reflected the issues around community reintegration of a patient with a stroke in poor socioeconomic rural and urban areas however the OM still needed to be taken through a rigorous process of statistical validation to establish that it was indeed valid. The following quotes illustrate this point:

> *Expert 1: I think so but you would need to examine the validity (criterion and construct validity) to answer this question with certainty.*
>
> *Expert 2: Yes, but still need to take it through the rigorous process to test its validity and reliability.*

One expert felt that it could be used for other pathologies other than stroke;

> *Expert 4: Yes, I agree, I think it does measure community reintegration in SA context...You would probably find it could later be extended to other acquired pathologies, to not just stroke…lots of post-graduate and collaboration opportunities.*

One expert felt that this OM could also be used in other countries as illustrated in the quote below:

> *Expert 3: Yes the tool does measure community reintegration in a South African context (rural and urban)- it can also be used in other developing countries with a similar setting to South Africa-actually your post doctoral can be testing it in one or two other SADEC countries and beyond-that is where the collaboration will start.*

4.7.3 **Domains**

Please note, only the domain similarities were noted and discussed at this validation stage of the development of the OM. The differences and contextual issues of the entire OM will be discussed in Chapters 6 and 7 after FA has been conducted.

The domains in this OM were as follows:

4.7.3a **Domain One: Activities of Daily Living and Personal Care (nine items)**

The activities of daily living and personal care are the activities that are mostly affected in one's life following a stroke. In this study, nine items were included in this domain. The items ranged from being able to get up and out of bed to being able to move around in one's community. This domain was also included in the RNLI as self-care and daily activities (Wood-Dauphnee et al, 1988). In the SIS version 3.0, the same domain was included as activities you might do during a typical day (Duncan et al; 2001). Although these are activities of daily living, which have to do with personal care they are just as important to community reintegration as other social and civic activities are to a person who has had a stroke.

4.7.3b **Domain Two: Home and Family Responsibilities (11 items)**

This domain represents all the tasks or activities that are done at home and for the family. Both the group of experts and patients raised several issues regarding this domain and the items contained. The issues raised were that some items were very specific to the rural setting as opposed to urban areas and vice versa; some items were very gender specific and lastly a distinction had also to be made in knowing whether the person had actually done some of these tasks prior to his/her stroke. In comparing this domain to other OM, RNLI included this domain and titled it "Indoor activities" and family roles (Wood-Dauphnee et al, 1988). On the other hand, CIQ has a domain named "home reintegration" which refers to the person's ability to do household chores and care for self and children (Willer et al, 1994). Similarly, the SIPSO has a domain named "activities (in and outside home)" Trigg and Wood (2000). The SIS-version 3.0 included items from this domain under the title "activities you might do during a typical day" (Duncan et al; 2001). These tasks are equally important as a measure of independence around the home, the ability to be able to perform these tasks also indicate a certain level of reintegration at home.

4.7.3c **Domain Three: Community and Social Responsibilities (four items)**

In both the rural and urban settings, there were some expectations and roles that need to be fulfilled in the community e.g. being able to attend functions such as weddings, funerals and community/civic meetings. This domain represents all the typical tasks or activities to be done in both rural and urban communities. Four items were included in this domain. This domain is similar to the "community" domain in the RNLI (Wood-Dauphnee et al, 1988). Willer et al, (1994) in the CIQ titled this domain as "social", referring to the ability to be able to do shopping, visit relatives, friends and undertake leisure activities. Although some of the examples given in the CIQ are more applicable to the recreation and leisure domain of this newly developed OM. The SIS-version 3.0 termed this domain "the ability to participate in the activities that you

usually do" (Duncan et al; 2001). The PS named this domain "community life" (Van Brackel et al, 2006a). The ability to get outside one's home into the community is a measure of community independence outside the patient's home which can assist with social isolation.

4.7.3d **Domain Four: Relationship (nine items)**

Relationships can be disrupted after stroke. The nine items in this OM are related to the participant's satisfaction with relationship to self and others e.g. intimacy with spouse, general communication with other people. Different outcome measures use different titles or names to define items contained in this domain for example in the RNLI it is termed "personal relationships" (Wood-Dauphnee et al, 1988). The SIPSO uses the heading "interaction" which refers to relationships to self and others (Trigg and Wood, 2000). Duncan et al; (2001) titled this domain as "ability to communicate with other people" in SIS-version 3.0, whereas the CIM defines this domain as "social support" which refers to both close and diffuse relationships (McColl et al, 2001). Lastly, the PS uses the term "relationship" to define relationships, (Van Brackel et al, 2006a).

4.7.3e **Domain Five: Travel/Transport (three items)**

The three items in this domain relate to travelling and the use of transport. The one item in particular refers to the family being able to assist participants with travel needs. In South Africa, travelling from one area to the other can be difficult due to a lack of an efficient and reliable public transport system. As a result, people who live in outlying areas like Soweto use taxis to get around. Taxis in these areas transport a number of people at any one time and are used extensively by people living in the area (these taxis were introduced as a result of inefficient and unreliable public transport in SA i.e. socio-political). From personal experience and information from the interviews most patients with a stroke find it hard, to move around using taxis as the taxi drivers are very impatient with patients who are disabled. In certain instances, they are made to pay for any assistive device such as wheelchairs as these devices take up a lot of space in the taxi. Only two other OM included this domain; in the RNLI it is called "distant mobility" (Wood-Dauphnee et al, 1988) and in the SIS-version 3.0 it is termed **"**the ability to be mobile at home and in the community" (Duncan et al; 2001).

4.7.3f **Domain Six: Recreation and Leisure (three items)**

The role of recreation and leisure must not be underestimated in assisting with community reintegration of a person with a stroke (Parker, 1997). In the first study of this thesis, patients were asked to explain their typical day but unfortunately, most patients were not fully occupied during the day. Three items were included to capture this domain. The one item focuses on

indoor recreation and leisure activity and the other two items focus on outdoor activity. Most outcome measures have this domain included as can be seen below:

- RNLI: recreational and social activities (Wood-Dauphnee et al, 1988).
- CIQ: social, referring to the ability to be able to do shopping, visit relatives, friends and undertake leisure activities (Willer et al, 1994).
- SIPSO: leisure (Trigg and Wood, 2000).
- SIS-version 3.0: ability to participate in the activities that you usually do (Duncan et al; 2001).
- CIM: occupation in this instance refers to leisure and productivity (McColl et al, 2001).
- PS: recreation and leisure (Van Brackel et al, 2006a).

4.7.3g **Domain Seven: Work and Education (two items)**

This domain included two items, one on return to work for participants who were working before their stroke or were doing volunteer work. The other item relates to the participants who still need to continue with their education basic, tertiary, or adult education. The outcome measures below have included these items:

- CIQ: Productivity, which refers to the ability of a person to work and do voluntary, jobs (Willer et al, 1994).
- SIS-version 3.0: ability to participate in the activities that you usually do (Duncan et al; 2001).
- CIM: occupation in this instance refers to productivity (McColl et al, 2001).
- PS included education, work and economic productivity (Van Brackel et al, 2006a).

4.7.3h **Domain Eight: Psychological Adjustment/Coping (three items)**

The rationale for including this domain in the outcome measure is that mental attitude and status are very helpful in determining the level of community reintegration of a person with a stroke, even though the functional abilities are just as important to also consider. Three items related to psychological adjustment and, coping have been included in this domain. These are related to the ability to remain optimistic about ones medical condition in terms of recovery. The other two are related the ability to remember events and being able to make decisions about one's life. Only the RNLI: General coping skills (Wood-Dauphnee et al, 1988) and the SIS-version 3.0: Memory and thinking (Duncan et al; 2001) included these items.

4.7.4 Scoring System

In the third round of the Delphi technique, the experts were asked to suggest a scoring system. A 4-point Likert scale for domains one, two, three, five, six, seven and a 3 point Likert for domain four and eight was adopted resulting in the following scoring system:

Items in domains one, two, three, five, six, seven are scored using a simple 4 point Likert scale as follows:

- No (0 point)

The “yes” response would have to be qualified by stating the extent to which the item, affects the patient’s community reintegration after stroke, as stated below:

- Able to with major help (one point)
- Able to with minor help (two points)
- And able to with no help (three points)

Items in domain four are scored using a 3 point Likert scale as follows:

- Not satisfied (0 point)
- Satisfied (1 point)
- Very satisfied (2 points)

The items in domain eight are scored as follows:

Item one

- Not at all (0 point)
- Somewhat (1 point)
- Definitely (2 points)

Item two and three of domain eight are scored as follows:

- Not at all (0 point)
- To some extent (1 point)
- To a full extent (2 points)

Justification for adoption of the scoring system:

Although the experts suggested other scoring systems, the researcher, psychologist and the statistician had to choose the most appropriate and simple (not too many Likert scales/points), based on the target population that the OM was going to be used for, taking into account literacy levels, the ease of translation to the most common spoken languages and

psychometrically sound response scale. Van Brackel et al., (2006b) in a letter to the editor of the journal of disability and rehabilitation suggested that the scoring system of an outcome measure developed for use in low and middle-income countries should be simple and straightforward, not requiring complicated calculations or computer software. This advice was taken into consideration when the scoring system of this outcome measure was developed.

4.8 CONCLUSION

The aim of study two was to establish the face and content validity of the new OM as well as to reduce items contained in the OM. The initial preliminary OM had eleven domains and 60 items. Three rounds of the Delphi technique with a group of experts, and two meetings using the nominal technique with a group of patients who have had a stroke were conducted in order to validate this OM and reduce the number of items in this OM. The final product (OM) from this process comprised of eight domains and 44 items. The scoring system was also finalised. The naming of the OM was not finalised as one expert suggested it should be delayed until the whole item reduction process was complete. The next step in the development of the OM was to conduct a factor analysis to further reduce items, group the items appropriately as well as to assess the internal consistency of the items contained in the OM. This process is presented in Chapter (5).

CHAPTER 5

5. STUDY TWO: VALIDATION STUDY

PHASE TWO: ITEM REDUCTION USING FACTOR ANALYSIS AND INTERNAL CONSISTENCY STATISTICS

5.1 INTRODUCTION

This chapter will present the internal consistency statistics and factor analysis used to validate the content of the items contained in the outcome measure thus enabling item reduction and better grouping of the items. Included in this chapter will be the justification for using factor analysis; the details of the study as well as the translation process of the OM.

5.2 JUSTIFICATION FOR USING FACTOR ANALYSIS

To ensure the construct validity of an instrument, one needs empirical evidence to show that the tool or instrument is measuring what it is intended to measure. According to Streiner and Norman, (2003:6) "Construct validity *indicates that items that make up an instrument adequately sample the universe of the content that defines the variable being measured".*

FA was used to establish construct validity of this OM. FA is a data reduction technique. It takes a large set of variables and looks for a way in which the data may be reduced or summarised using a smaller set of factors or components. This is an almost impossible task to do by eye with anything more than a small number of variables (SSPS, 2007: 179-199).

The term "factor analysis" encompasses a variety of different, although related techniques. One of the main distinctions of these techniques is between what is termed principal component analysis (PCA) and FA. These two sets of techniques are similar and are used interchangeably by researchers. Both attempt to produce a smaller number of linear combinations of the original variables in a way that captures most of the variability in the pattern of correlation (SSPS, 2007: 179-199). In this study, FA was used to examine the factor loadings to provide information on the underlying dimensions of the measure and an estimate of construct validity (Nunnally, 1978).

5.3 METHOD

5.3.1 Objective

Following the process of validation and item reduction in Study 2 phase one, with the experts and patients, the numbers of items in the outcome measure were still considered to be too many. In addition that the questionnaire would take too long time to administer.

Therefore, the objectives of this phase of the study were three fold:

- To continue with the item reduction process;
- To better group the items and
- To quantitatively validate the items contained in the outcome measure as well as establish the homogeneity of items contained in the OM.

5.3.2 Study Design

A quantitative, cross sectional study design was used.

5.3.3 Study Setting

The study was conducted in a community setting, in primary health care (PHC) clinics, hospitals and in patients' homes in both rural and urban areas.

5.3.4 Sample and Inclusion Criteria

Please note: Patients who participated in this study did not participate in the qualitative (study 1) and nominal group technique (study 2, phase 1). Based on the number of items contained in the outcome measure, 100 patients per setting were required to conduct factor analysis (Nunnally, 1978).

The sample was made up of:

- Patients with a stroke who were above the age of 18 years.
- In the case of patients with expressive or receptive aphasia the caregiver only was interviewed.
- The patients were members of the community in which he/she lived pre-morbidly.
- The patients had lived for six months to one year in their community following their stroke. Six months to one year has been found to be an adequate period for reintegration into a community following stroke (Stark et al, 2005).

5.3.5 **Patients Were Excluded if they had the Following**

- Had been admitted to a nursing homes,
- Had no local family carer and the patient had aphasia,
- Were medically unstable (self report),
- Had major medical problems not related to stroke (self report).

5.3.6 **Patient Recruitment and Setting**

Patients were recruited from PHC clinics in Soweto in the Gauteng province and in Elim/Siloam in the Limpopo province of South Africa. In both provinces, patients were recruited from clinics that were not used in Study 1. The respective provinces and clinic managers were asked for permission to carry out the study in their clinics. Once permission was granted, physiotherapists working in these clinics were approached to provide the researcher with a list of patients with stroke attending the clinic as well as those they were visiting at home. The resident physiotherapist initially approached potential participants and their caregivers to ask them individually to participate in the study. Patients and caregivers were given the study information sheet and if they agreed to participate in the study were asked to sign the study consent form (See appendix 5.1 and 5.2).

5.3.7 **Data Collection: Procedure**

5.3.7.1 **The process for translation of the new outcome measure**

The newly designed outcome measure was taken through the process of translation before use in this study.

Due to the high illiteracy rate in South Africa, outcome measures written in English need to be translated into a variety of local languages. In South Africa 32% of the adult population are regarded as being functionally illiterate and of this percentage black South African's illiteracy rate is over 20% (Aitchison & Harley 2004). Therefore, written communication needs to be in the local language to further aid those who are illiterate.

In the Gauteng province of South Africa, the most commonly spoken African languages are IsiZulu and South Sotho, whereas in the Limpopo province the most common languages are XiTsonga, TshiVhenda and North Sotho (Aitchison & Harley 2004). Translating questionnaire-based outcome measures is important to avoid the use of terminology and concepts that are foreign to patients and that enable them to answer as accurately as they can (Akinpelu et al., 2007). The following steps as adapted from Beaton et al. (2000) were followed in this translation process with minor modifications as indicated below.

Step one:

Eight translations of the outcome measure were undertaken; two for each of the target languages (IsiZulu, South Sotho, Xitsonga and Tshivenda); one translated by an informed health professional (namely physiotherapist speaking the language) and the other translated by an uninformed translator (i.e. a non-medically trained person speaking the language).

Step two:

A common translation from each pair of the eight translators was produced, resulting in four translations.

Step three:

To check the reliability of the translation process, the four local language translations were back translated to English by professional translators.

Step Four:

For the purpose of data collection for the factor analysis study the version of the outcome measure after step two in the translation step was used. A pilot study was not conducted using this version as the outcome measure was not at its final stage for piloting, as the scoring system still needed to be finalised and it was expected that some items may have had to be changed following the factor analysis. A copy of the English version at step 2 can be seen in appendix 5.3 and an example of the Sesotho version can be seen in appendix 5.4.

5.3.7.2 **Procedure for training research assistants in the rural area**

Data collection in the urban area was collected by the researcher alone; therefore, there was no need for training. The training of research assistants to collect data for this study in the rural areas was done prior to the commencement of the study. The research assistants were senior physiotherapists who worked in two of the local district hospitals. These research assistants were chosen because of their willingness to assist with this study; they came from the same area and spoke the local language.

The training included the following:

- Explaining the aim of the study and how this part of the study fitted within the whole study
- Explaining the importance of using validated measures in rehabilitation and describing the intent of the new OM.
- Delineating the ethical issues and how to obtain informed consent from participants for this study.

- How to collect the demographic information from participants using the demographic data sheet before the interviews began.
- The process of interviewing using the newly developed questionnaire.
- Describing the different domains of the outcome measure and the scoring system for each domain and item.
- At the end of the session, the research assistants were given the opportunity to ask questions and discuss any issues of concern.

5.3.7.3 **Procedure for data collection for this section (study 2, phase 2)**

- The purpose of the study was explained to patients and caregivers.
- Patients' consent was obtained prior to administering the new outcome measure (see Appendix 5.1 and 5.2).
- Patients' demographic data were captured prior to interviewing the patients using a standardised form used in the previous study (see Appendix 3.14).
- Patients were given an option to be interviewed with the OM translated into their language or English see appendix 5.3 and 5.4.
- Inter-rater reliability was done in the rural areas because there was more than one research assistant who collected data. To establish the Inter rater reliability of the OM for a rural cohort the researcher and research assistants collected data for the first 10 patients independently.
- Intra-rater was done in the urban area because the researcher was the only one who collected data, so similarly to establish intra-rater reliability of the OM for an urban cohort the researcher collected data for 12 patients in the urban setting and one day later the researcher collected data on the same 12 patients again.
- After the results of inter and intra-rater reliability were analysed, the differences were highlighted and outlined (see the results section)
- Data for factor analysis were then collected using the outcome measure.

5.3.7.4 **Procedure for statistical analysis**

- Firstly initial internal consistency was established to assess the homogeneity of the items before factor analysis could be conducted.
- Then the factor analysis was undertaken.
- Once all factor analysis data were analysed the items were re-grouped according to the factors they were loading on or put into factors where they seemed to make logical and theoretical sense according to the construct being measured.

- The internal consistency was conducted again to reassess the homogeneity of these newly grouped items per factor before finalising the groupings of the items contained in the outcome measure.
- The overall internal consistency was then established for both the rural and urban outcome measures.

5.4 STATISTICAL TESTS USED TO ANALYSE THE DATA

Statistical tests used to analyse the data are presented below according to the procedures followed in this study. The STATA (version 10) package was used to analyse data.

5.4.1 **For Demographic Data**, descriptive statistics and frequency tables were used in describing data.

5.4.2 For Intra and Inter-Rater Reliability

There are a number of ways in which reliability can be established. Stability examines the reproducibility of a measure administered on different occasions (Streiner and Norman, 2003). The different types of reliability are test-retest, inter-rater and intra-rater reliability. Intra-rater reliability measures the consistency of the same assessor for the same patients assessed on two separate occasions, whereas inter-rater reliability measures the consistency between two assessors for the same patients assessed at the same time (Streiner and Norman, 2003). The marginal homogeneity (Stuart-Maxwell) test was used with the significance set at a p-value equal to or less than 0.05 to determine the level of agreement between the raters.

5.4.3 For Internal Consistency

Internal consistency is another way of establishing reliability of an outcome measure. Internal consistency is measured from a single administration of the measure, and it investigates the extent to which all the items making up the scale measure the same construct. Internal consistency is generally analysed using Cronbach coefficient. Acceptable reliability of instruments developed for research purposes can be as low as 0.70 although 0.90 is a generally accepted threshold for internal consistency (Streiner and Norman, 2003).

While Cronbach alpha gives an indication of overall consistency, it does not provide information about which items may be inconsistent and, thereby, contribute error to the instrument. Another approach to examining internal consistency or homogeneity is item-total/rest correlations. In this method, each item is correlated to the total test score. Generally item-total/rest correlations should yield correlations between 0.70 and 0.90 (Streiner and

Norman, 2003; Kielhofner, 2006). The advantage of item-total/rest correlation is that it allows an instrument developer to identify individual items that may be inconsistent with the total score and, thereby, contribute to error of the instrument (Kielhofner, 2006).

5.4.4 **Factor Analysis**

There are three numeric values to use when considering factor analysis, the Eigen value, which reflect the amount of variance accounted for by each factor, Eigen values of 1.0 or more are retained (SSPS, 2007). Factor loadings, which represent the correlation between each item and each factor, usually a factor loading of 0.30 or less is not meaningful (Kielhofner, 2006). In cases when the same item has a factor loading above 0.30 for more than one factor, the judgement is made by placing the item in the factor for which it has the higher of the two factor loadings (Kielhofner, 2006). Lastly, rotation of factor loadings is done to identify meaningful factors that include highly correlated items of the factor. Although there are several ways to do factor rotation, the most common is varimax (orthogonal) rotation (SSPS, 2007; Kielhofner, 2006). The SSPS (version 17) package was used to analyse data.

The results of study 2 phase 2 are presented below.

5.5 **RESULTS**

The results are presented according to the procedure followed in this study. The section below presents the results of the translation process.

5.5.1 **Translation Process**

The differences from the two translation process i.e. between the two translators (the health professional and the lay person) of the four languages are documented below along with the resultant changes for each of the four languages. The adoption of acceptable phrases or words was based on the grammatical correctness and written phrases or words in the language as advised by language translators.

Table 5.1: Translated Southern Sotho Demographic Information

Original version	Translator 1	Translator 2	Acceptable word/phrase: Final version
Gender	Botho	Bong	Bong
Race	Mmala	Morabe	Morabe
Level of formal education obtained	Dilemo tsa thuto	Boiphitlhelo ba tsa thuto	Boiphitlhelo ba tsa thuto
Name of the interviewer	Lebitso la mohlaba dipotso	Lebitso la mohlahlobi	Lebitso la mohlaba dipotso
Location of the interview	Tulo ya dipotso	Sebaka sa hlahlobo	Sebaka moo ho boditsewng di potso
Instructions to the patient	Melao ho mokudi	Ditaelo ho mokudi	Ditaelo ho mokudi

Table 5.2: Translated South Sotho Items

Original version	Translator 1	Translator 2	Acceptable word/phrase: Final version
Since your stroke	Ho tloha o tshwere ke stroke	Ka morao ha hobana le stroke	Ka morao ha ho shwa letlhakore
1.1 Are you able to get up and out of bed	Na o kgona ho tsoha le ho tswa dikobong 111ag ag?	O kgona ho tswa dikobong?	Na o kgona go tsoha le ho tswa dikobong 111ag ag?
1.2 Are you able to move around uneven/hilly area?	Na o kgona ho itsamaisa ditulong tse nang le makukuno?	O kgona ho tsamaya dibakeng tse moepa?	Na o kgona ho itsamaisa ditulong tse nang le makukuno le moepa?
1.9b Are you able to move around your yard?	Na o kgona ho itsamaisa jarateng ya hao?	O kgona ho tsamaya serapaneng 111ag ago?	Na o kgona ho itsamaisa jarateng ya hao?

Table 5.3: IsiZulu Translation

Original version	Translator 1	Translator 2	Acceptable word/phrase: Final version
1.9b Are you able to move around your yard?	Uya kwazi ukuhamba egcekeni?	Uya kwazi ukuhamba ejaratini yakho?	Uya kwazi ukuhamba ejaratini yakho?

Table 5.4: TshiVhenda Translation

Original version	Translator 1	Translator 2	Acceptable word/phrase: Final version
Side of hemiplegia	Lurumbu lwo hemiplegia	Lurumbi lwo omaho	Lurumbi lwo omaho

Table 5.5: XiTsonga Translation

Original version	Translator 1	Translator 2	Acceptable word/phrase: Final version
How long have you been living in this community?	I nkarhi wo tanihi kwihi mi rikarhi mi tshama endhawini leri?	I nkarhi wo tanihi kwihi mi rikarhi mi tshama tikweni leri?	I nkarhi wo tanihi kwihi mi rikarhi mi tshama endhawini/ tikweni leri?
1.9b Are you able to move around your yard?	Xana wa swi kota ku fambafamba e mugangeni laha mitshaka kona?	Xana wa swi kota ku fambafamba e tikweni laha mitshaka kona?	Xana wa swi kota ku fambafamba a tikweni/endawini laha mitshaka kona?

Results and summary of the training of research assistants are briefly presented.

5.5.2 Training of Research Assistants

Items to be used in the interview as well as the scoring system for each were largely understood except for the following items:

- First item in domain four. The assistants had concern with item D4Q1, as this is an item that deals with sexual issues and was considered culturally inappropriate in both the urban and rural areas.
- Item two in domain five, seemed to require a yes or no response and not a four point Likert scale.
- Items D7Q1 and D7Q2 in domain seven, seemed to require an additional response of “not applicable” for some patients, especially if they were old and widowed. The decision was however made to interview using the questionnaire as is, despite the above objection as experts and patients validated these items.
- The statistician’s advice was sought in the final analysis (see results).

The next section will present the demographic characteristics of the participants of this study.

5.5.3 Demographic Characteristics of the Participants

A total of 216 patients were included, 112 patients from the urban area and 104 from the rural area. The numbers of patients to include in this study for factor analysis was based on the number of items contained in the OM (Nunnally, 1994).

The demographic characteristics of the participants are presented in the tables below.

Table 5.6: Patient Demographic Characteristics

	Urban n=112 (%)	Rural n=104 (%)	Total (%)
Age Category			
30 years and less	7 (6%)	5 (5%)	12 (6%)
31-45 years	30 (27%)	14 (13%)	44 (20%)
46-60 years	49 (44%)	34 (33%)	83 (38%)
Greater than 60 years	26 (23%)	51 (49%)	77 (36%)
Total	112 (100%)	104 (100%)	216 (100%)
Gender			
Male	61 (55%)	47 (45%)	108 (50%)
Female	51 (46%)	57 (55%)	108 (50%)
Total	112 (100%)	104 (100%)	216 (100%)
Marital status			
Single	48 (43%)	14 (14%)	62 (29%)
Married	46 (41%)	59 (57%)	105 (49%)
Separated	3 (3%)	2 (2%)	5 (3%)
Divorced	2 (2%)	2 (2%)	4 (2%)
Widow	13 (12%)	27 (26%)	40 (19%)
Total	112 (100%)	104 (100%)	216 (100%)
Side: Hemiplegia			
Left	67 (60%)	45 (43%)	112 (52%)
Right	45 (40%)	59 (58%)	104 (48%)
Total	112 (100%)	104 (100%)	216 (100%)
Range of duration of Hemiplegia	1995-2009	2000-2009	
Caregiver			
Yes	100 (89%)	82 (79%)	182 (84%)
No	12 (11%)	22 (21%)	34 (16%)
Total	112 (100%)	104 (100%)	216 (100%)
Education level			
Primary	41 (37%)	63 (61%)	104 (48%)
Secondary	68 (61%)	37 (36%)	105 (49%)
Tertiary	3 (3%)	4 (4%)	7 (3%)
Total	112(100%)	104(100%)	216(100%)

Table 5.6 continues

Current employment status	**Urban n=112 (%)**	**Rural n=104 (%)**	**Total (%)**
Unemployed	93 (83%)	45 (43%)	138 (64%)
Employed	4 (4%)	7 (8%)	11 (5%)
Retired	15 (14%)	52 (50%)	67 (31%)
Total	112 (100%)	104 (100%)	216 (100%)
Previous employment			
Never worked	18 (16%)	29 (28%)	47 (22%)
Blue collar	84 (75%)	68 (65%)	152 (70%)
White collar	8 (7%)	5 (5%)	13 (6%)
Students	2 (2%)	2(2%)	4 (2%)
Total	112 (100%)	104 (100%)	216 (100%)
Who was interviewed			
Patient	100 (89%)	84 (81%)	183 (85%)
Caregiver	5 (5%)	10 (10%)	15 (7%)
Both	7 (6%)	10 (10%)	17 (8%)
Total	112 (100%)	104 (100%)	216 (100%)
Where Interview took place			
Clinic	92 (82%)	6 (5.7%)	98 (45%)
Home	20 (18%)	77 (74%)	97 (45%)
Hospital	0	21 (20%)	21 (10%)
Total	112 (100%)	104 (100%)	216 (100%)
How long had participants lived in the community?			
1-5 years	19 (17%)	5 (5%)	24 (11%)
6 or more years	93 (83%)	99 (95%)	192 (89%)
Total	112 (100%)	104 (100%)	216 (100%)

Summary of Table 5.6

Thirty eight percent of the participants were in the age category 46 to 60 years, although the rural cohort had 49% above the age of 60 years. It was also interesting to note that 12% of the participants were below the age of 30 years. The urban setting had slightly more male (55%), whereas the rural cohort had slightly more female participants (55%). Most of the participants in both provinces (49%) were married; however, in the rural setting there were more widows (26%) than in the urban setting (12%).

In the rural setting there were almost equal numbers of patients with right hemiplegia (58%) as opposed to the urban setting which had more patients with left hemiplegia (60%). Eighty four percent of patients in both settings had a caregiver at home, whereas 15% had no caregivers.

Sixty percent of the participants in the rural setting had only attained a primary level of formal education, whereas 68% in the urban setting attained a secondary level of education. Only 3% of participants in both settings had attained a tertiary level of formal education. Only 5% of participants were employed at the time of the study in both settings, and 50% were retired in the rural setting. Seventy percent were labourers in both settings.

Eighty five percent of the participants (patients did not have expressive nor receptive aphasia therefore there was no need to interview caregivers) in both setting were interviewed. In the rural setting most of the interviews took place at the patient's home (74%), whereas in the urban setting 82% took place at the local primary health care (PHC) clinic. None of the interviews took place at a hospital in the urban setting.

Eighty eight percent of participants in both settings had been living in the community for more than six years following stroke.

The section below will presents the results of the intra and inter-rater reliability analysis.

5.5.4 **Intra/Inter Reliability**

5.5.4.1 **Intra-rater reliability**

- There was perfect agreement (r=0.95, p value=0.01) on all the items.

5.5.4.2 **Inter-rater reliability**

- There was perfect agreement on all the items except for item below:
  - Dq1_6: "Are you able to drink from a cup or glass". The (r= 0.30; p 0.04).

The results of the internal consistency are presented in the next section below.

5.5.5 **Internal Consistency**

Due to the excessive number of tables in this section of this chapter only tables indicating internal consistency of the urban and rural settings for domain one will be presented as examples and the rest of the tables have been placed in Appendix 5.5 but comments relating to these results will be presented here.

Overall Cronbach alpha values that approach 0.90 are indicative of a high homogeneity of items contained in the scale. Both the overall Cronbach alpha and "item-rest correlations" were used to examine internal consistency of the domains. Item-rest correlations should yield correlations between 0.70 and 0.90 (Norman and Streiner, 1995), item-rest correlations as low as 0.6 are also acceptable. The advantage of using item-rest correlation over Cronbach alpha is that it allows an instrument developer to identify individual items that may be inconsistent with the total score thereby, contributing error to the instrument (Kielhofner, 2006).

Tables 5.7 below present the results of the internal consistency per domain and setting. Table 5.7 indicates the internal consistency of domain one for the urban setting.

Domain 1 Activities of Daily Living and Personal care

Table 5.7: Internal Consistency for Domain One: ADL and Personal Care for the Urban Cohort (n=112)

Item number	Number of Observations	Item-Rest Correlation	Cronbach Alpha
D1Q1	112	0.82	0.93
D1Q2	112	0.76	0.93
D1Q3	112	0.79	0.93
D1Q4	112	0.82	0.93
D1Q5	112	0.71	0.94
D1Q6	112	0.71	0.94
D1Q7	112	0.44	0.95
D1Q8	112	0.78	0.93
D1Q9	112	0.88	0.93
D1Q10	112	0.85	0.93
D1Q11	112	0.75	0.94
Test scale			0.94

The overall Cronbach alpha was good for this domain for the urban setting (0.93). All the items had a high correlation (range: 0.93 - 0.94) except for item seven, whose item–rest correlation was low (0.44).

Table 5.8 indicates the internal consistency for domain one for the rural setting.

Table 5.8: Internal Consistency for Domain One: ADL and Personal Care for the Rural Cohort (n=104)

Item number	Number of Observations	Item-Rest Correlation	Cronbach Alpha
D1Q1	104	0.80	0.93
D1Q2	104	0.77	0.94
D1Q3	104	0.83	0.93
D1Q4	104	0.81	0.93
D1Q5	104	0.61	0.94
D1Q6	104	0.74	0.94
D1Q7	104	0.43	0.95
D1Q8	104	0.79	0.94
D1Q9	104	0.84	0.93
D1Q10	104	0.82	0.93
D1Q11	104	0.78	0.94
Test scale			0.94

Similar to the urban setting the overall Cronbach alpha was good for this domain (0.94). All the items were correlated except for item seven, whose item–rest correlation was again low (0.43).

Table 5.9 (Appendix 5.5) indicates the internal consistency for domain two (Home and family responsibilities) for urban participants. The overall Cronbach alpha was good for this domain (0.91). All the items had a high consistency (range: 0.89 - 0.92) except for items eight, 10 and 11, whose item–rest was low (0.54 and 0.44 respectively).

Table 5.10 (Appendix 5.5) indicates the internal consistency for domain two (Home and family responsibilities) for rural participants. The overall Cronbach alpha was good in this domain (0.90). All the items had high consistency (range: 0.85 - 0.91) except for items eight, 10 and 11; the item-rest correlation was low (0.48 and 0.28 respectively).

Table 5.11 (Appendix 5.5) indicates the internal consistency for domain three (Community and social responsibilities) for the urban setting. The overall Cronbach alpha was good in this domain (0.88). All the items in this domain were homogenous.

Table 5.12 (Appendix 5.5) indicates the internal consistency of domain three (Community and social responsibilities) for the rural cohort. All the items in this domain were related and consistent with Cronbach alpha ranging from 0.81 to 0.93.

Table 5.13 (Appendix 5.5) indicates the internal consistency of domain four (Relationship) for the urban cohort. The following items one, three, six, seven and nine had low item-rest correlation (0.26, 0.50, 0.57, 0.50 and 0.47 respectively) although the overall Cronbach alpha for this domain was still acceptable (0.85).

Table 5.14 (Appendix 5.5) indicates the internal consistency for domain four (Relationship) for the rural cohort. The following items, one, six and nine had low item-rest correlation (0.36, 0.57 and 0.28 respectively). The overall Cronbach alpha was acceptable (0.87).

Table 5.15 (Appendix 5.5) indicates the internal consistency for domain five (Travel and transport) for the urban cohort. In this domain, all items were related (range of item-rest correlation: 0.67 – 0.83).

Table 5.16 (Appendix 5.5) illustrate the internal consistency for domain five (Travel and transport) for the rural cohort. Items two and three had a low item-rest correlation (0.51 and 0.54) but the overall Cronbach alpha was acceptable (0.74).

Table 5.17 (Appendix 5.5) indicates the internal consistency for domain six (Recreation and leisure) for the urban cohort. Item one had low item-rest correlation (0.51). The overall Cronbach alpha was acceptable (0.78).

Table 5.18 (Appendix 5.5) illustrates the internal consistency of domain six (Recreation and leisure) for the rural cohort. The overall Cronbach alpha for the domain was very low (0.53). All the items in this domain had low item-rest correlation (range: 0.20 – 0.40).

There were only two items in domain seven (Work and education); in the urban setting both items had a good overall Cronbach alpha (0.91) for the urban cohort. All items in this domain were related.

The two items in domain seven (Work and education), in the rural setting both had low overall Cronbach alpha (0.57).

Table 5.19 (Appendix 5.5) indicates the internal consistency for domain eight (Psychological adjustment and coping) for the urban cohort. Only item one had low item-rest correlation (0.52), the Cronbach alpha of this domain was acceptable (0.80).

Table 5.20 (Appendix 5.5) indicates the internal consistency for domain eight (Work and education), for the rural cohort. Items one and three had low item-rest correlation (0.49 and 0.59) and item two had low Cronbach alpha (0.57).

The factor analyses results are presented in the section below.

5.5.6 **Factor Analysis**

Principal component analysis with a varimax rotation (oblique oblimin 0.2) was computed on eight factors. The Kaiser-Meyer-Olkin (KMO value) measure of sampling adequacy was 0.832. As the Barlett's test of sphericity was significant (p-value= 0.03), it was therefore appropriate to conduct factor analysis.

The scree tests for the urban and rural cohorts (see Figure 5.1 and 5.2 respectively) suggested on 8-factor solution i.e. eight factors had Eigen values greater than one in both the urban and rural settings. These eight factors explain a total of 86.20% and 84.12% of the variance in the urban and rural settings respectively. Below are the scree plots indicating the eight retained factors in both settings.

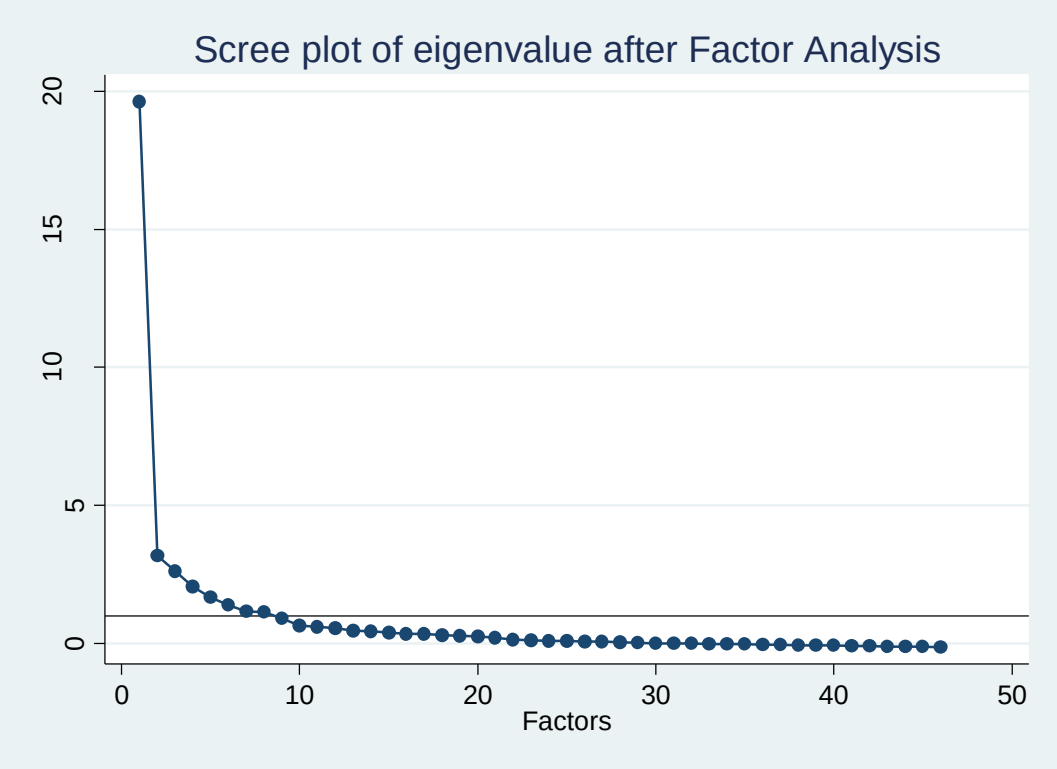


Figure 5.1: The Scree Test for the Urban Setting

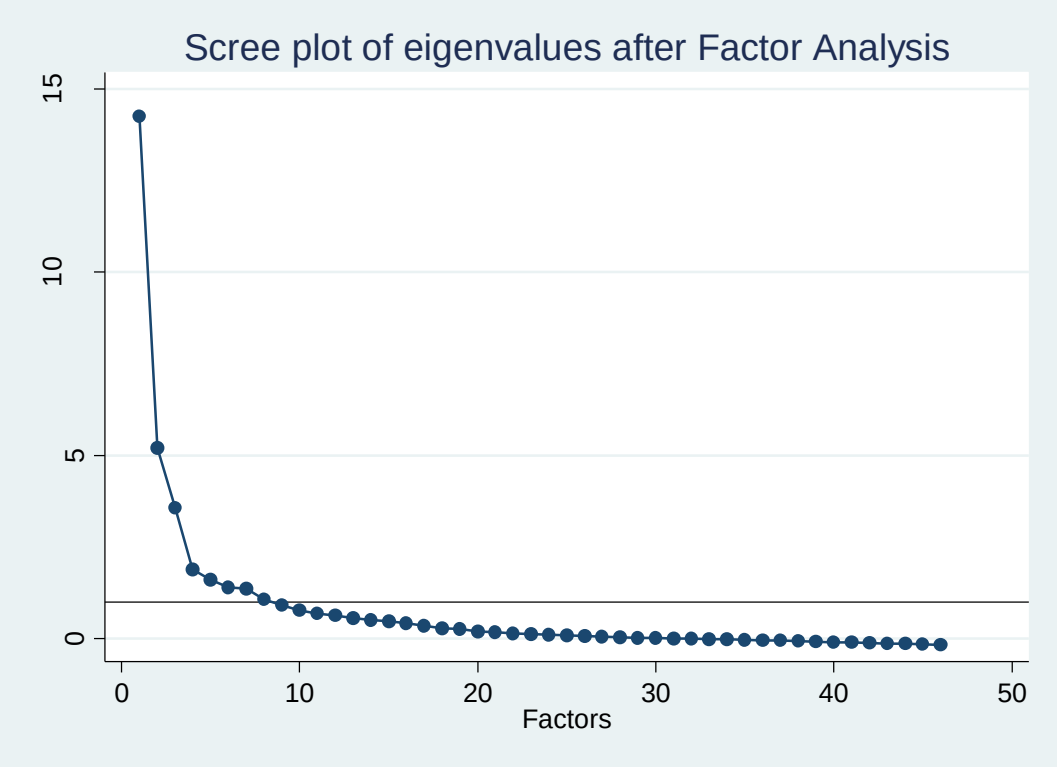


Figure 5.2 The Scree Test for the Rural Setting

Due to the excessive number of tables in this section of this chapter only tables indicating rotated factor loadings of the urban and rural settings will be presented as an example for factor I and the rest of the tables have been placed in Appendix 5.6. The results will however be commented upon below.

In this section the word “factor” is used to present the results. A “factor” is not similar to a “domain” as presented earlier in the other sections of this study; hence the word domain is not being used in this section. FA uses mathematical calculations/models to come up with “factors”. Once all factors that belong together are regrouped, only then can they be given a domain name. The results are shown in the tables below according to the way the expert and patients grouped the items in phase one of validation study 2.

Factor I

The factor loadings are presented as four decimal places and are not rounded off. Table 5.21 below indicates the rotated factor loading for factor one of the urban cohort.

Table 5.21: Rotated Factor Loadings for Factor I for the Urban Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq1-1	0.7672							
Dq1-2	0.6169							
Dq1-3	0.4607							
Dq1-4	0.5859							
Dq1-5	0.7873							
Dq1-6	0.7628							
Dq1-7	-							0.4441
Dq1-8	0.8088							
Dq1-9	0.9257							
Dq1-10	0.9388							
Dq1-11	0.8030							

All the items were retained and loaded on factor one except for item seven that loads on factor eight.

Table 22 below indicates the rotated factor loading for factor I for the rural the cohort.

Table 5.22: Rotated Factor Loadings for Factor I for the Rural Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq1-1	-			0.7411				
Dq1-2	-		0.4051					
Dq1-3	-			0.5002				
Dq1-4	-			0.5744				
Dq1-5	-			0.9097				
Dq1-6	-			0.9472				
Dq1-7	-			0.4371				
Dq1-8	-		0.5412					
Dq1-9	-		0.6546					
Dq1-10	-		0.7725					
Dq1-11	-		0.7058					

All items were retained but loaded on different factors, with most loading on factor three and four.

Table 5.23 (Appendix 5.6) presents rotated factor loadings results of factor II for the urban setting. All items were retained but loaded onto different factors. Item one loaded on factors two and three.

Table 5.24 (Appendix 5.6) presents the rotated factor loadings results of factor II for the rural setting. All items were retained in this factor; however all loaded onto different factors. Items one and two loaded on factor seven, item eight loaded on factor seven and item 10 loaded on factors seven and eight.

Table 5.25 (Appendix 5.6) presents the rotated factor loadings results of factor III for the urban setting. All items were retained in this factor but all loaded on factor two.

Table 5.26 (Appendix 5.6) presents the rotated factor loadings results of factor III for the rural setting. All items were retained in this domain but all loaded on factor two.

Table 5.27 (Appendix 5.6) presents the rotated factor loadings results of factor IV for the urban setting. All items were retained in this factor, however most loaded onto different factors. Items

four and five did not load onto any factor. Item one loaded on factors two and eight and item three loaded on factors two and three.

Table 5.28 (Appendix 5.6) presents rotated factor loading results of factor IV for the rural setting.
Item one did not load on any factor and the rest of the items loaded onto factor five except for item nine which loaded on factors three and eight.

Table 5.29 (Appendix 5.6) presents the rotated factor loading results of factor V for the urban setting. All the items were retained in this factor and loaded onto factor one however item two loaded on factors one and five.

Table 5.30 (Appendix 5.6) presents the rotated factor loading results of factor V for the rural setting. All items loaded on different factors but item three loaded on both factors one and two.

Table 5.31 (Appendix 5.6) presents the rotated factor loading results of factor VI for the urban setting. None of the items loaded on factor six but item three loaded on factors one and two.

Table 5.32 (Appendix 5.6) presents the rotated factor loading results of factor VI for the rural setting. None of the items loaded on factor six.

Table 5.33 (Appendix 5.6) presents the rotated factor loading results of factor VII for the urban setting. Both items were retained in this factor and they both loaded on factor seven.

Table 5.34 (Appendix 5.6) presents the rotated factor loading results of factor VII for the rural setting. Both items were retained but item one did not load on factor seven only on factor eight.

Table 5.35 (Appendix 5.6) presents the rotated factor loading results of factor VIII for the urban setting. All items were retained in this factor but item two and three loaded on factor five as well.

Table 5.36 (Appendix 5.6) presents the rotated factor loading results of factor VIII for the rural setting.
All items in this domain were retained but none loaded on factor eight. Item three loaded on factors five and six.

5.5.7 Summary of Factor Analysis Results

The FA suggested a new grouping of the items that were retained. According to the FA, the items which seem to belong together were combined to make one factor as shown in the Tables (37-44 in Appendix 5.7). These new groupings were not similar for both setting, hence each setting ended with a different version of the OM (the rural and the urban versions), due to the way the items were grouped together. Following the re-grouping of these items, the internal consistency was assessed for these newly grouped items before giving names to the factors (now to be termed domains) and the results of the internal consistency are shown in the tables below.

5.5.8 Internal Consistency of the Newly Grouped Items per Factor

Due to the excessive number of tables in this section of this chapter only tables indicating internal consistency of urban and rural settings will be presented as an example for factor I and the rest of the tables will be placed in Appendix 5.8, however they have been commented on below.

In both settings, factors with an overall Cronbach alpha above 0.70 were retained; in the case where a factor had low overall Cronbach alpha correlations, the items with a low item-rest correlation were removed from that factor. The researcher used his discretion to make the decisions.

Table 5.45 below present the newly grouped factor's internal consistency for Factor I in the urban setting version.

Table 5.45: Internal Consistency for Factor I Urban Setting Version (n=112)

Item	Number of Observation	Item - Rest Correlation	Cronbach Alpha
Dq1- 1	112	0.79	0.96
Dq1- 2	112	0.79	0.96
Dq1- 3	112	0.78	0.96
Dq1- 4	112	0.82	0.96
Dq1- 5	112	0.65	0.96
Dq1- 6	112	0.64	0.96
Dq1- 8	112	0.82	0.96
Dq1- 9	112	0.90	0.95
Dq1- 10	112	0.88	0.95
Dq1- 11	112	0.82	0.96
Dq2- 8	112	0.72	0.96
Dq2- 9	112	0.63	0.96
Dq5- 1	112	0.85	0.96
Dq5- 3	112	0.80	0.96
Dq6-1	112	0.72	0.96
Dq6-3	112	0.72	0.96
Total scale			0.96

Factor one has excellent overall internal consistency (0.96) and all items were related (range of item-rest correlation: 0.62 – 0.90).

Table 5.46 below presents the newly grouped factor's internal consistency for Factor I in the rural setting version.

Table 5.46: Internal Consistency for Factor I Rural Setting Version (n=104)

Item	Number of Observation	Item - Rest Correlation	Cronbach Alpha
Dq2-1	104	0.76	0.90
Dq2- 2	104	0.65	0.91
Dq2- 3	104	0.61	0.91
Dq2- 4	104	0.82	0.90
Dq2- 5	104	0.77	0.90
Dq2- 6	104	0.78	0.90
Dq2- 7	104	0.75	0.90
Dq2- 8	104	0.57	0.91
Dq2- 9	104	0.66	0.91
Dq5- 3	104	0.53	0.91
Total score			0.91

Factor one has excellent overall internal consistency (0.91).

Summary of the internal consistency presented in the tables above and tables in Appendix 5.8 (Tables 47-57):

The following factors had good to excellent overall internal consistency for the urban version of the OM: Factors I, II, III, V, VI, VII (0.96, 0.87, 0.92, 0.86, 0.83 and 0.91 respectively). Factor VIII yielded very poor/low overall internal consistency (0.49) for the urban version therefore items Dq1-7 and Dq8-1 were removed (reasons for this are given in the discussion section below) from the final urban version of the OM.

The following factors had good to excellent overall internal consistency for the rural version of the OM: Factors I, II, III, IV, V, and VI (0.91, 0.87, 0.89, 0.90, 0.90 and 0.75 respectively). Factor VII and VIII yielded moderate to very poor/low overall internal consistency for the rural version (0.67 and 0.35 respectively). The following items (Dq1-7, 2-10, 2-11, 5.2, 6-2, 6-3, 7-1 and 7.2) were subsequently removed from the final rural version of the OM except for Dq7-1, 7-2 (reasons for this are given in the discussion section below).

The section below will discuss the above results presented.

5.6 DISCUSSION

In Chapter 4, the structure of the OM was finalised and was put through rigorous statistical tests in Chapter 5. The first statistical test conducted was internal consistency, followed by FA. After FA, the items were re-grouped. Each setting ended with a different version and the second internal consistency was done again for these two versions of the OM. The discussion section below is presented according to the procedure followed in this study. The translation of the OM will be discussed first, followed by the training of assistants, intra and inter-rater reliability, the demographic characteristics of the patients, the initial internal consistency, FA, the second internal consistency after regrouping the items and lastly summary of the items that were removed from each version of the OM (the rural and urban setting versions).

5.6.1 Translation Process

Translation of instruments/OM is necessary especially when a tool is developed in a different language, culture and context; however the translation process can in itself alter the tool. In this study the IsiZulu, TshiVhenda and XiTsonga translations were more accurate (from the back translation) than the South Sotho translation, which was shown to have a number of discrepancies. This would appear to be due to problems between the two translators and the written versus the spoken South Sotho language and semantics. One South Sotho translator used spoken language more than written language. Typographical and minor grammatical changes were made to all translations to enhance clarity and readability of the translated versions. In this study, the adoption of acceptable phrases or words was based on the grammatical correctness and written phrases or words in the language as advised by language translators.

Berkanovic, (1980) acknowledges that the translation process still poses a limitation, without rigorous back-translation and pretesting the instrument may be interpreted differently in the new language. Even if the translation is adequate, cultural differences can adversely affect an instrument's properties (Deyo, 1984). To be fully confident of an instrument's validity in a new language or culture, a complete repetition of the validation process is required as shown in this study (Nord, 1991). Once the outcome measure has been translated successfully then users should be trained to use it appropriately. The next section discusses the results pertaining to training of assistants on the administration of the outcome measure in this study.

5.6.2 Training of Research Assistants

The training of the research assistants was conducted to ensure that the data collection was carried out properly and in a similar manner for both settings. The results from this training indicated that there were two items that needed the response scale to be rephrased for patients. These items required a dichotomous response, but were not changed. The decision was however made to interview using the questionnaire as is despite the objection as experts and patients validated these items. The last item in the new outcome measure needed the researchers (both settings) to be sensitive in asking the item as it deals with issues of intimacy. This was because in many cultures it is inappropriate and taboo to ask or even discuss intimacy issues with an older person (Lo et al, 2001).

The next section discusses the results of the intra and inter-rater reliability testing.

5.6.3 Intra/inter Reliability

5.6.3.1 Intra-rater reliability

There was 100% agreement on all items. The reason is two pronged, firstly an experienced researcher collected the data and secondly, the data were collected two days apart. A retest interval of two to 14 days is usual (Streiner and Norman, 2003).

5.6.3.2 Inter-rater reliability

Item Dq1_6 was the only item in the first domain that was found to be problematic from a reliability perspective between the two researchers in the rural setting i.e. the researcher and research assistant. The item asked about the ability of the patient to drink water from a cup or a glass. The researcher gave lower scores as compared to the research assistant for this item. It is not clear why this item had a poor inter-reliability. The speculation is that most patients were not able to do this task but explained how they actually accomplished the task but in essence, they were not able to. The decision was to firstly ask the question with a yes or no answer, if yes how, is it with major help, minor help or no help at all.

The next section discusses the characteristics of the participants.

5.6.4 Demographic Characteristics of the Participants

Twenty five percent of participants were below the age of 45 years. Thirty one percent of those below the age of 45 were in the urban areas. Although only one patient disclosed being HIV positive, the lower ages in the urban cohort may be attributed to HIV/AIDS which has changed the epidemiological picture of stroke (Connor et al, 2004; Mudzi, 2009), with young people

presenting with a stroke, thus this needs to be taken into consideration when assessing community reintegration following stroke, as reintegration strategies may be different for different age groups.

Most patients (84%) in both settings had a caregiver. In a recent study of Mamabolo et al., (2008) it was shown that patients with stroke tend to depend on their caregivers and this dependency has a negative impact on community reintegration (Mamabolo et al, 2008). The reason for this dependency on caregivers is cultural. Families ensure that the patients have a family member to look after them, and this caregiver may "not allow" the patients to do things for themselves as some of the quotes from the qualitative study (study 1 in chapter 3) bore this out.

Forty eight percent of patients in both settings had only primary school education; the majority of whom came from the rural areas (60%). A lower education may impact on a patient's ability to complete self administered questionnaires. This finding supports the idea of an interviewer administered outcome measure for patients who have poor literacy skills.

Sixty three percent of potentially employable patients were unemployed, though 21% of these patients had not worked ever before their stroke. The majority of patients who were employed prior to their stroke were blue collar workers (70%). One aspect of positive community reintegration is return to work, not only does it enhance self esteem, return to work also assists in ensuring financial stability (Wolfenden and Grace, 2009). There are no employment figures on return to work for patients with stroke in SA, that the researcher is aware of but the suspicion is that it is low or non-existant. The current employment figures on return to work following stroke obtained by Varona et al, 2004 in Madrid (Spain) is 53%, although adjustments were necessary for 23% of them. Return to work may not be an achievable option in our SA context unless return to work rehabilitation strategies are developed and implemented to increase employment options.

The urban patients in Soweto were able to attend a stroke group at their local clinic; this option was not available to the rural patients living in Elim and Siloam. Stroke groups at the rural PHC clinics may have been available but the distances people have to travel to get to these clinics are great, and if people cannot walk there then it becomes impossible for a person to attend. As a result, the patients in the rural setting tended to receive more home-based therapy than clinic or hospital-based therapy. Home-based rehabilitation versus clinic/hospital-based rehabilitation is a topic of controversy. Whilst home-based rehabilitation provides the

opportunity for the therapists to work with the person in the context of their homes, patients often prefer to go to the institutions to allow them to get out of the home and reduce/increase socialisation (Von Koch et al, 1998).

The majority (88%) of the patients had been living in their community for more than six years in both settings after their stroke. Six months to one year has been found to be an adequate period for reintegration into a community following stroke (Stark et al, 2005).

The next section presents the results of the internal consistency testing.

5.6.5 Internal Consistency (first/initial)

Please note, items were not removed from the OM during the first internal consistency testing. FA had to be done first before deciding on retention or discarding of items. This is due to the fact that the item may have a high factor loading and belongs to another domain within the OM, therefore, only FA could assist with the regrouping of items before the decision could be made to remove or retain the item.

5.6.5.1 Domain 1 activities of daily living and personal care

The overall internal consistency in both settings for this domain was very good (0.94), indicating that the items were related. In both settings, item seven, however had a very low item-rest correlation (0.44 urban and 0.43 rural). This result may be because the item did not belong to this domain but to another domains within the outcome measure, or that the item did not measure the construct of community reintegration. If this item were to be left in this domain, it would introduce error and would reduce the internal consistency of this domain. Item seven assesses the patient's ability to write or draw a cross which is a skill required for signature. Both the experts and the patients suggested this item be placed in this domain, because it was viewed as an upper limb functional task which most items included in this domain were. It is not clear why this item had a low correlation but it may be that signing a form is considered more of a cognitive task than upper limb task. None of the outcome measures reviewed has this item included in the scale.

5.6.5.2 Domain 2 home and family responsibilities

This domain assesses the ability to fulfil home chores and responsibilities. The overall internal consistency in both settings was good in this domain (0.91 urban and 0.90 rural). The item-rest correlation for items eight (055 for urban and rural), 10 (0.54 urban and 0.48 rural) 11 (0.44 urban and 0.28 rural) were low for both settings in this domain. Item eight assesses the

patient's ability to collect water from the river and the communal tap, a possible reason for this low correlation could be that most patients in this study have access to tap water in their own homes and thus did not have to travel to the river or communal tap to get water as was originally assumed and suggested by the qualitative cohort (study 1) for consideration to include in the OM.

Item 10 assesses the patients' ability to take care of their livestock for example cattle, goats, sheep and dogs. It was suggested by the qualitative cohort (study 1) for consideration to include in the OM. The reason for this poor correlation could be that most patients in this study did not actually have livestock to take care of. In the rural setting members of the patient's extended family may have taken over this task. Therefore may be this item is not required to be in the OM.

The last item in this domain that had low item-rest correlation was item 11 for both settings. This item assesses the ability of the patient to teach children traditional home keeping tasks. This item was suggested and considered by the experts and patients in Study 1 to be important, but perhaps it no longer is in contemporary South Africa especially the urban areas. One old lady in an interview (Study 1) also attributed this role loss to children not willing to learn traditional tasks due to western influences. Therefore, this item was considered for removal from this domain.

5.6.5.3 **Domain 3 community and social responsibilities**

The overall internal consistency in both settings was good for this domain (0.93 urban and 0.88 rural). The item-rest correlation of each item correlated highly (range of item-rest correlation: 0.73 – 0.90 urban and 0.62 – 0.87 rural) with the rest of the items in this domain in both settings, indicating that these items belonged together. This domain assesses the ability of the patient to fulfil community and social responsibilities such as being able to attend community gatherings for example religious, weddings, meetings, parties or funerals. These tasks are seen as being very important and contextual activities in both settings. In both settings, there are unspoken and unwritten expectations of the community for one to attend these activities especially funerals as non-attendance is viewed as being unsociable (personal experience).

5.6.5.4 **Domain 4 relationships**

This domain assesses the satisfaction with the social interactions and relationships, relationships in this instance referring to the ability to relate to other people like spouses, children, family members or people in the community. In both settings, item one in this domain

had a very low item-rest correlation (0.26 urban and 0.36 rural). Removing item one may improve the overall internal consistency of this domain. This item assesses the satisfaction of the patients with matters of intimacy with spouses. Both the research assistants and patients had a problem with this item as it bordered on privacy and is culturally inappropriate. The dilemma is whether to include or exclude this item as it was raised in the interviews by some of the young patients in urban setting as being a problem affecting their community reintegration. It was therefore considered that FA may assist in making this decision.

In both settings, item six yielded a low item-rest correlation (0.57). This item assesses the patient's satisfaction with his/her visitors. In retrospect, the item was not phrased correctly; it needed to be rephrased as to clearly state as to what about the visitors the patients were satisfied or not.

Item seven yielded a low item-rest correlation (0.50) in the urban setting. This item assesses the patient's satisfaction with the help and support received from relatives and friends. The item also had a low correlation with the rest of the items in the urban setting. Eleven percent of the patients in the urban setting did not have caregivers. In the urban areas, many of the patients were not staying with their family members as they had come to Johannesburg to work and the rest of the family were back at their home in the rural areas. Additionally, as they were not from the city, they did not have a sense of community around them or know the people very well in the local city community. These patients felt that they had few support structures and networks in the urban areas. On the contrary, patients in the rural area enjoyed support from their extended family and community at large. The other reason for the low item-rest correlation could be that the item did not specify the kind of help and support patients received, and when the questionnaire was administered, the researchers and research assistants had to give examples of help and support in order for the patients to respond to this item. In contrast, item two of domain five which specifies the kind of help the patients were receiving from family and friends required a "yes" or "no" response. It would appear that item two was out of place in domain five, the suggestion was to combine these items with item seven, domain four, into one and then leave it in domain four.

Item nine also had very low item-rest correlation (0.47 urban and 0.28 rural) in both settings. This item assesses the satisfaction and ability to physically assist other people. The main reason for this low item-rest correlation could be due to the fact that most patients in this study still needed help themselves with most ADL, let alone being able to assist others.

5.6.5.5 **Domain 5 travel and transport**

Even though the overall internal consistency was acceptable (0.87) for this domain in the urban setting it was felt that, the removal of item two may improve its internal consistency further. Items two and three had low item-rest correlations in this domain in the rural setting (0.54 and 0.51 respectively). Item two assesses the financial support patients required when travelling. This item was suggested by the expert panel, to acknowledge that financial difficulties may affect community reintegration; an example being when patients need to travel to a clinic or the hospital to collect medication. The patient may have to catch a taxi but may not have money to do so. In certain instances patients have to pay for their assistive devices like a wheelchair as it occupies a space that may have been occupied by another person. The item assesses whether the family assisted in this regard. However, the nuances of this enquiry may not have been conveyed by the item's question.

Item three assesses the patient's ability to use the transport, they had used prior to the stroke. This item's correlation with the rest of the items was low in the rural setting. This may be because most patients were not able to use transport either due to their limited mobility to get to the transport or that they lived in remote villages that do not have access to public transport and therefore, this item was considered for removal from this domain.

5.6.5.6 **Domain 6 recreation and leisure**

All three items for this domain had low item-rest correlation (0.20, 0.40 and 0.45) and low overall internal consistency (0.53) in the rural setting but for the urban setting only item one had low item-rest correlation (0.51). Item one assesses the patient's ability to do an activity for self enjoyment e.g. watching television or listening to the radio. The other two items assess the ability to be involved in physical activity such as playing a sport and getting out of the house to go shopping in town, going out with friends or to watch a soccer match at a stadium. The age of the patient in this study could be the reason for this cohort not seeing any reason for leisure activities after the stroke. From the demographics section of this study, patients in the rural setting were older and retired therefore their response to these questions may make these items seem not important for community reintegration. The second reason could be that leisure and recreation is defined differently by patients in the rural setting as opposed to patients living in an urban setting. In addition, people in the rural areas do not have access to as many recreation and leisure facilities as compared to the people living in an urban setting. Lastly, the lack of finances also contributes significantly in this case, as most patients are poor. Again, it was considered that these items may have to be removed from the domain for both settings, although it will be a great omission to remove this item which is extremely important and core

to community reintegration in the context of patients living in poor socioeconomic areas (ICF, 2001).

5.6.5.7 **Domain 7 work and education**

This domain has two items, which assess the patient's ability to return to work and education. The urban setting yielded a good overall internal consistency (0.91) for this domain, whereas a low overall internal consistency (0.57) was yielded in the rural setting. The reason for this low internal consistency in the rural setting could be due to the fact that the majority of patients (49%) in the rural areas were retired and they no longer worked or were involved in education (formal or informal) so thus these two items were not applicable. An interesting observation shared by the research assistants from the rural cohort was that even though some of the patients were still in the working or school-going age groups they indicated their intentions as not wanting to go back to work or school but to get a disability grant from the provincial government. For the rural people it may be too difficult to get to school or get to work and thus just easier to get grants, as opposed to really not wanting to work/be educated. Although these two items did not yield a good overall internal consistency in the rural areas, the participants in the rural areas expressed the need to return to work or school during the interviews in study 1, therefore it was felt that these items should not be removed from the outcome measure in the rural setting. It would be great omission to remove these two items which are extremely important and core to community reintegration (WHO, 2001; Van Brackel et al, 2006).

5.6.5.8 **Domain 8 psychological adjustment and coping**

In both settings, the overall internal consistency for this domain was acceptable (0.80 urban and 0.75 rural) however item one in this domain had a low item-rest correlation (0.52 urban and 0.49 rural) in both settings. It was felt that removing this item would improve the internal consistency of this domain. The item assesses the patient's ability to hope that he/she will get better. The basis of this item is complex, as it may have something to do with the state of mind at the time; it could be affected by many factors such as the level of independence and support that is received from the family, or be affected by co-morbidity such as depression. It may be that item one is too simply stated to capture the complexity of what it is asking. Item three in the rural setting had low item-rest correlation (0.59) and Cronbach alpha (0.64). Item three established the ability to make decisions regarding life and family issues. It was felt that this item may have to be removed from this domain for the rural setting, as it could introduce error in this domain.

The next section presents the discussion of factor analysis.

5.6.6 Factor Analysis

This section continues to answers one of the objectives of this study which was to validate the contents of this newly developed outcome measure. This has been done by further reducing items and better grouping of items. In this section, each factor will be discussed in both the rural and the urban setting OM using the rotated factor loadings as presented in the results section of this study. The discussion focuses on the decision taken with regards to item retention or removal. In cases when the same item has a factor loading above 0.30 for more than one factor, the judgement was made by placing the item in the factor for which it had the higher of the two factor loadings (Kielhofner, 2006).

For the discussion below, see tables (5.21 to 5.36).

5.6.6.1 Factor I (see tables 5.21 and 5.22)

In the urban setting all items were retained in this factor except for item seven which was felt to be retained in factor eight as it loaded more there. Item seven assesses the patient's ability to write or draw a cross, which is a skill required for signature. Both the experts and the patients suggested this item be placed in this domain, because it was viewed as an upper limb functional task which most items included in this domain.Retaining this item in this factor reduced the internal consistency of items contained in this domain as shown in the internal consistency section above. The item was retained as its factor loading was above 0.3. On the other hand, in the rural setting all items were retained, however, the items were loading on different factors with most loading on factors three and four. Items in this factor assess the ability to perform ADL and self care. The items ranged from being able to get up and out of bed to being able to move around in one's community. This domain was also included in the RNLI as self-care and daily activities (Wood-Dauphnee et al, 1988). In the SIS version 3.0, the same domain was included as activities you might do during a typical day (Duncan et al; 2001). Although these are activities of daily living, which have to do with personal care they are just as important to community reintegration as other social and civic activities are to a person who has had a stroke.

5.6.6.2 Factor II (see tables 5.23 and 5.24)

In the urban setting, items in this factor loaded more on factor three and the rest were spread between factors one, two and six. Item one loaded more on factor three and was retained in this factor. Item one assesses the ability to clean one's house and yard. Home and family responsibilities are also important for community reintegration of a person with a stroke. Being able to take care of the surroundings is one of the indicators of successful community

reintegration. In the rural setting most factors loaded on factor one, with item one loading on factors one and seven but it was retained in factor one. Item two loaded more on factor one and was retained in factor one. Item eight loads more on factor one and was retained in factor one. Item 10 was retained in factor seven. Items one, two, eight, ten and eleven assess the ability to clean the house and yard, work in the field or garden, collect water from a tap or river, take care of livestock and teach children housekeeping tasks. All these items are tasks that are very specific to a rural community setting.

5.6.6.3 **Factor III (see tables 5.25 and 5.26)**

All items were retained but they all loaded on factor two for both the urban and rural setting. Items in this factor assess the ability of the patient to attend to community and social responsibilities e.g. attending funerals in the community. Item two specifically assesses the ability of the patient to attend burial societies, social clubs or any other meetings in the community. In most poor or low socioeconomic areas of South Africa, people in the communities have developed many different ways of assisting each other in times of bereavement such as contributing money to a funding scheme prior to death in a family. They are expected to attend a physical, face to face meeting at different locations on a monthly basis. Non attendance is punished in the form of a fine which could range from R10 (South African Rand) to R100; therefore, one needs to attend to avoid this fine.

5.5.6.4 **Factor IV (see tables 5.27 and 5.28)**

In the urban setting the items were scattered and loaded on different factors but all items were retained because of their high factor loadings. Item one loaded on factor two and eight but was retained in factor two as it loaded more there than in factor eight. Similarly item three loaded more on factor three than two and was retained in factor three. Items four and five did not load on any factors and were discarded from the domain; these items assess the satisfaction of the patient about communication with family and others. A possible reason for no factor loadings on these items is that the patients were so isolated that they only communicated with family members. The other three items (six, seven and eight) loaded on factor five, thus they were retained in this factor.

In the rural setting, the picture is completely different as most factors loaded on factor five. Item one was not loading on any factor; this item established the patients' satisfaction with intimacy with their spouse and it was therefore discarded. As previously mentioned there was concern expressed about talking to elders about their intimate issues, as this is a taboo subject. Another possible reason for poor factor loading for this item could be that most patients in the

rural areas were widowed (Table 5.6); therefore this part of their lives was nonexistent. It can generally be concluded that most patients were uncomfortable to talk about intimacy issues, as this is culturally inappropriate (Lo et al, 2001). Although the ICF (WHO, 2001) includes intimacy under participation, it appears that in the context of our patients this item should be excluded from both versions of the outcome measure (the rural and the urban).

5.6.6.5 **Factor V (see tables 5.29 and 5.30)**

The items in this factor assess the patient's ability to use the transport they used before their stroke. All items were retained in this factor, however, in the urban setting item two loaded on factor one and five therefore, was retained in factor five as it loaded more there. As for the rural setting, item two loaded on factor seven but item three loaded on factors one and two and was retained in factor one. Transport and travelling is a huge issue in a country like South Africa. Most people especially in poor rural and urban settings have to travel long distances to access public transport to get anywhere. Of major medical, concern is getting to a clinic to collect medication. One of the reasons for patients to default on their treatment is the distance from the patients' home to a PHC clinic (Hasker et al, 2008).

5.6.6.6 **Factor VI (see tables 5.31 and 5.32)**

In the urban setting, item two loaded on factor two and item three was retained in factor one as it loaded more there than on factor two. In the rural setting, items one, two and three loaded on factors four, eight and seven respectively. The items in this factor assess the recreation and leisure patterns of the patients. During the interviews conducted in study one, it was discovered that most patients were not productively occupied during the day. Leisure and recreation activities could assist in community reintegration (Parker et al., 1997) because it has been shown that participating in leisure and recreation activities is closely associated with life satisfaction and is a worthwhile and measurable goal of rehabilitation (Parker et al, 1997).

5.6.6.7 **Factor VII (see tables 5.33 and 5.34)**

Items one and two loaded on factor seven in both settings; with the exception of item one in the rural setting which loaded on factor eight. Items one and two in this factor assess the ability of the patient to return to work or some form of education (school, higher education including adult education programmes). As the sample comprised both participants, who are working and those who were still attending some training, it is important to include these two items in the outcome measure. Returning to work for people with stroke may contribute significantly to their life satisfaction, well being, self-worth and social identity, giving them an opportunity to maintain independence as far as physically possible with the income generated through

employment (Wolfenden and Grace, 2009). Return to work may be seen as an indication of the recovery of a patient with stroke. In the context of SA's epidemiological transition (due to HIV and AIDS) there are more young patients who are affected by stroke (Connor et al, 2004, Mudzi, 2009). Return to school or university for these young people may be a good indicator of successful community reintegration.

5.6.6.8 **Factor VIII (see tables 5.35 and 5.36)**

Items two and three were retained in factor five as they loaded more there than in factor eight, whereas item one was retained in factor eight for the urban setting. In the rural setting, all items were retained in factor six including item three as it loaded more on this factor than factor five. Items in this factor assess the patients psychological and memory status i.e. being hopeful of getting better and remembering events. The last item assesses the ability to make decisions. In the qualitative study (study 1), the participants in both settings expressed feelings of hopelessness and helplessness, especially about being able to recover. In the researcher's opinion, the participants in this study were focused more on the difficulties under the circumstances they faced by living in poor socioeconomic areas. Therefore, they saw life in a very negative way, were not able to cope and subsequently lost hope. The items in this factor will potentially assist therapists in assessing the psychological status of the patients prior to rehabilitation.

The section below discusses the results of the second internal consistency test that was conducted after the regrouping of items following the factor analysis.

5.6.7 **Discussion of the Internal Consistency after Regrouping of the Items**

The newly grouped items were assessed for internal consistency again to confirm homogeneity (internal consistency) of the new groupings. The overall Cronbach alpha of the factor was used to make a final decision with regards to the removal of items from both OM (the rural and the urban).

In the urban setting the following factors had good to excellent overall internal consistency Factors I (0.96), II (0.87), III (0.92), V (0.86), VI (0.83), VII (0.91). Therefore, all items in these factors were retained as part of the new outcome measure according to the new groupings for urban setting OM. However, Factor VIII yielded poor internal consistency (0.49) for the urban setting OM therefore items Dq1-7 and Dq8-1 were removed. These items would have introduced errors if left in the measure. The item Dq1-7 assesses the ability to write or draw a cross and Dq8-1 assesses whether the patient is hopeful of getting better. In the initial internal

consistency, both items Dq 1-7 and Dq8-1 yielded poor item-rest/total correlation, (0.49) and (0.52) respectively. Therefore, the second internal consistency confirmed that these two items do not belong to the urban OM.

In the rural setting the following factors had good to excellent overall internal consistency Factors I (0.91), II (0.87), III (0.89), IV (0.90), V 0.90), and VI (0.75). Therefore, all items in these factors were retained as part of the new outcome measure according to the new groupings for both settings. However, Factor VII (0.67) and VIII (0.35) yielded poor internal consistency for the rural setting. The following items (Dq1-7, 2-10, 2-11, 5.2, 6-2, 6-3, 7-1 and 7.2) were subsequently removed from the final rural outcome measure with the exception of items Dq7-1 and 7-2 because, as discussed earlier, these two items assess the ability to return to work and school/university or a training programme which is considered important. It was therefore felt that these items should remain in the rural setting outcome. These two items are extremely important and core to community reintegration (WHO, 2001; Van Brackel et al, 2006).

Similary the following items Dq1-7 (0.43), Dq2-10 (0.54), Dq2-11 (0.44), Dq5.2 (0.52), Dq6-2 (0.40) and Dq6-3 (0.45) yielded low item-rest/total correlation in the rural setting when the inital internal consistency was tested, therefore, the second internal consistency confirmed that these items do not belong to the rural setting OM.

The next section presents a summary of the items removed from the OM (both versions), the overall internal consistency and the naming of the OM.

5.6.8 Summary: The Items Removed from the Outcome Measure and the Overall Internal Consistency of the New Outcome Measure

From the whole item reduction process (factor analysis and internal consistency) in this chapter, the two settings had their own outcome measures, due to the new grouping of the items following FA. In the rural setting 12 items were removed from the OM, leaving 34 items. Six items were removed from the urban version of the OM, leaving 40 items. The items which were removed are presented in the table below.

Table 5.58: Items which were Removed from the Outcome Measures

Urban setting version	Rural setting version
Are you able to write or draw a cross?	Are you able to write or draw a cross?
Are you able to collect firewood, chop and prepare the fire?	Are you able to take care of your livestock?
How satisfied are you with your intimacy?	Are you able to teach children home keeping tasks?
How satisfied are you with your communication with family?	How satisfied are you with your intimacy?
How satisfied are you with your communication with people around you?	How satisfied are you with your ability to physically assist someone?
Are you hopeful that you will get better?	Are you able to get to the clinic/hospital to collect your medication or for rehabilitation/nursing/medical help?
	Are your friends and family assisting you with your travelling needs?
	Are you able to do a physical activity such as playing any sport?
	Are you able to get out of the house to go shopping in town or going out with friends or watch a soccer match at a stadium?
	Are you hopeful that you will get better?
	Are you able to remember things told and events easily?
	Are you able to make decisions regarding your life and family issues?

The items which form the final two outcome measure are shown in Appendix 5.9 (urban setting version) and Appendix 5.10 (rural setting version).

Both the rural and the urban setting versions' internal consistency was assessed. The overall internal consistency (all items), for both the rural and the urban setting versions was 0.95 indicating that the homogeneity of the items contained in each outcome measure was excellent.

At this stage, it was decided to name the outcome measure the Maleka Stroke Community Reintegration Measure (MSCRIM), the rural and urban versions as suggested by one expert in Chapter 4. The suggested name reflects three main points; first, "who" designed the OM (branding the OM), second for "whom" it was designed (the target group), patients with stroke, last "why" (the purpose) to assess their community reintegration. The country or place where the OM was developed was not included in the name, because in the development of the OM only two out of the nine South African provinces were included, although the results may be generalised to other SA provinces, as the settings are similar.

5.7 CONCLUSION

The aim of this phase of the study was to validate the contents and reduce the items contained in the newly developed outcome measure and to group items that belonged together. The tool was taken through a rigorous process of validation via the following steps:

- Translation of the tool to ensure that the outcome measure was in the language that the patients would be able to understand.
- Training of research assistants on the administration of the outcome measure to ensure consistency in the way data were collected.
- The inter- and intra-rater reliability were established to check the level of agreement between the researcher and research assistants as well as reproducibility of the results.
- The internal consistency of the outcome measure was established using alpha coefficients.
- FA, assisted in item reduction and better grouping of the items into the different domains.
- As a result, the two settings each ended up with different outcome measures. In the rural setting 12 items were removed, leaving 34 items but only six items were removed from the urban setting outcome measure, leaving 40 items.
- The newly grouped items were assessed for internal consistency again.
- The new outcome measure was named the Maleka Stroke Community Reintegration Measure (MSCRIM) and has two versions, a rural version and an urban version.

CHAPTER 6

6. STUDY TWO: VALIDATION STUDY
PHASE THREE: CONSTRUCT VALIDITY

6.1 INTRODUCTION

This chapter will present how the third phase of study 2 (construct validity) was conducted. Included in the presentation will be the justification for establishing construct validity and the details of this phase of Study 2.

6.2 OBJECTIVE AND JUSTIFICATION FOR THIS STUDY

The objective of this third phase of study 2 was to establish construct validity of the Maleka Stroke Community Reintegration Measure (MSCRIM) by comparing it with an existing tool of community reintegration, namely the Subjective Index of Physical and Social Outcome (SIPSO). The SIPSO is a 10 item assessment tool, used to assess an individual's ability to reintegrate to a "normal" lifestyle after a stroke (Trigg and Wood, 2000). The SIPSO was chosen because it is the only scale that was developed to measure participation, and its validity has been tested on patients with stroke including younger patients (Kersten et al, 2004). It does not take long to administer. Lastly, the SIPSO has a similar construct as the MSCRIM. It was hypothesized that the results of the MSCRIM would correlate with the SIPSO since the two measure a similar construct i.e. community reintegration, although the MSCRIM has many more items than the SIPSO.

6.3 METHOD

6.3.1 Study Design

A quantitative, cross sectional study design was used.

6.3.2 Study Setting

The study took place in a community setting, in primary health care (PHC) clinics, hospitals and patients' homes in both rural and urban settings.

6.3.3 Sample Size

Please note, patients who participated in this study did not participate in the qualitative (study 1), nominal group technique (study 2, phase 1) and factor analysis (study 2, phase 2).

A sample size of 80 patients (40 per setting i.e. urban and rural) was calculated to have 85% power to detect a moderate correlation coefficient of at least 0.4 (see analysis section of this chapter); a reasonable threshold value for the current scenario i.e. a moderate correlation between the two scales (n Query Advisor 7: a statistical package).

6.3.4 Inclusion Criteria

Inclusion criteria were the same as for the previous studies.

6.3.5 Patients were Excluded if they had the Following

Exclusion criterion were the same as for the previous studies.

6.3.6 Patient Recruitment and Setting

Patient recruitment and setting were similar to the previous studies.

6.3.7 Data Collection

6.3.7.1 Procedure

- The purpose (the information sheet) of the study was explained to patients and/or caregivers (see appendix 6.1).
- Patients' consent was obtained prior to administering the new outcome measure (see appendix and 6.2).
- Patients' demographic data, using a standardised form, were also captured prior to interviewing the patients.
- Patients were given an option to be interviewed with the translated (South Sotho, Xitsonga, TshiVhenda or Zulu version) of the MSCRIM or the English version.
- The SIPSO was translated into South Sotho, Xitsonga, TshiVhenda or Zulu. The same option was given to patients for the SIPSO (see appendix 6.3 and 6.4), even though the SIPSO is self-administered, in this study it was interview administered.
- For the participants in the rural areas, the MSCRIM (rural setting version) and the SIPSO (see appendix 6.5) were administered to participants by the same rater (trained research assistant) once.
- For the participants in the urban areas, the MSCRIM (urban setting version) and the SIPSO (see appendix 6.6) were administered to participants by the same rater once, namely the researcher.

6.4 ANALYSIS

The Pearson product moment correlation coefficient (r) was used to assess correlation between the total scores of the MSCRIM and the SIPSO. The interpretation of correlation coefficient is the strength of the relationship (Kielhofner, 2006). The STATA (version 10) package was used to analyse data.

6.5 RESULTS

A total of 80 patients were recruited, 40 patients from the urban and 40 from the rural areas. None of the patients were excluded as they all fitted the inclusion criteria. It took 15 to 20 minutes to administer both versions of the MSCRIM.

6.5.1 Participants' Demographic Characteristics

The table below presents the demographic characteristics of the participants.

Table 6.1: Patient Demographic Characteristics

	Urban n=40 (%)	**Rural n=40 (%)**	**Total (%)**
Age Category			
30 years and less	2(5%)	0	2(5%)
31-45 years	7(18%)	5(12%)	12(15%)
46-60 years	19(47%)	8(20%)	27(33%)
Greater than 60 years	12(30%)	27(68%)	39(47%)
Total	40(100%)	40(100%	80(100%)
Gender			
Male	13(32%)	14(35%)	27(34%)
Female	27(68%)	26(65%)	53(66%)
Total	40(100%)	40(100%)	80(100%)
Marital status			
Single	18(45%)	0	18(23%)
Married	16(40%)	22(55%)	38(47%)
Separated	0	3(7.5%)	3(4%)
Divorced	0	1(2.5%)	1(1%)
Widow	6(15%)	14(35%)	20(25%)
Total	40(100%)	40(100%)	80(100%)
Side: Hemiplegia			
Left	20(50%)	25(63%)	45(56%)
Right	20(50%)	15(37%)	35(44%)
Total	40(100%)	40(100%)	80(100%)
Range of duration of Hemiplegia	1999-2009	1997-2009	
Caregiver			
Yes	32(80%)	33(82%)	65(81%)
No	8(20%)	7(18%)	15(19%)
Total	40(100%)	40(100%)	80(100%)

Table 6.1 continues

	Urban n=40 (%)	Rural n=40 (%)	Total (%)
Education level			
Primary	20(50%)	27(67%)	47(58%)
Secondary	18(45%)	9(23%)	27(34%)
Total	40(100%)	40(100%)	80(100%)
Current employment status			
Unemployed	30(75%)	5(12%)	35(44%)
Employed	0	7(18%)	7(8.75%)
Retired	10(25%)	28(70%)	38(47%)
Total	40(100%)	40(100%)	80(100%)
Previous employment			
Never worked	6(15%)	6(15%)	12(15%)
Blue collar	32(80%)	28(70%)	60(75%)
White collar	2(5%)	6(15%)	8(10%)
Students	0	0	0
Total	40(100%)	40(100%)	80(100%)
Who was interviewed			
Patient	28(70%)	31(78%)	59(74%)
Caregiver	1(2%)	9(22%)	10(12%)
Both	11(28%)	0	11(14%)
Total	40(100%)	40(100%)	80(100%)
Where interview took place			
Clinic	27(67%)	0	27(34%)
Home	13(33%)	40(100%)	53(66%)
Hospital	0	0	0
Total	40(100%)	40(100%)	80(100%)
How long had participants lived in the community?			
1-5 years	9(23%)	1(2%)	10(13%)
6 or more years	31(77%)	39(98%)	70(87%)
Total	40(100%)	40(100%)	80(100%)

Summary of the participant's demographic characteristics:

In the rural setting most of the participants were older (68% were above the age of 60 years), than those in the urban setting (30% were above the age of 60 years). In both settings, there were more females than males and more married participants, but the rural setting had more widows than the urban setting.

Most participants in both settings had an informal caregiver at home. The level of formal education attained by most participants in the rural areas was a primary level as opposed to most participants in the urban areas who had attained a secondary level of formal education. Seventy five percent of the participants were unemployed in the urban setting compared with

12% in the rural setting, of whom 70% were retired. Most participants in both settings were manual labourers prior to the stroke.

All interviews were conducted at the participants' homes in the rural setting as opposed to 68% of the interviews in the urban setting done at a local PHC clinic. Most patients in both setting were able to communicate verbally; therefore very few caregivers who were interviewed. Most patients in both settings had been members of the community pre-morbidly and had lived in the community more than a year following their stroke.

The results of the correlation between the MSCRIM and the SIPSO are presented below.

6.5.2 **Construct Validity**

The results of the two versions of MSCRIM (rural and urban) are presented below.

6.5.2.1 **The MSCRIM (rural setting version)**

The correlation between the total scores of the MSCRIM (rural setting version, 34 items) and the SIPSO (10 items) was r = 0.95; p= 0.001 level (2-tailed), thus a very high correlation between the two outcome measures.

The figure below indicates the total scores of the MSCRIM (rural setting version) against SIPSO.

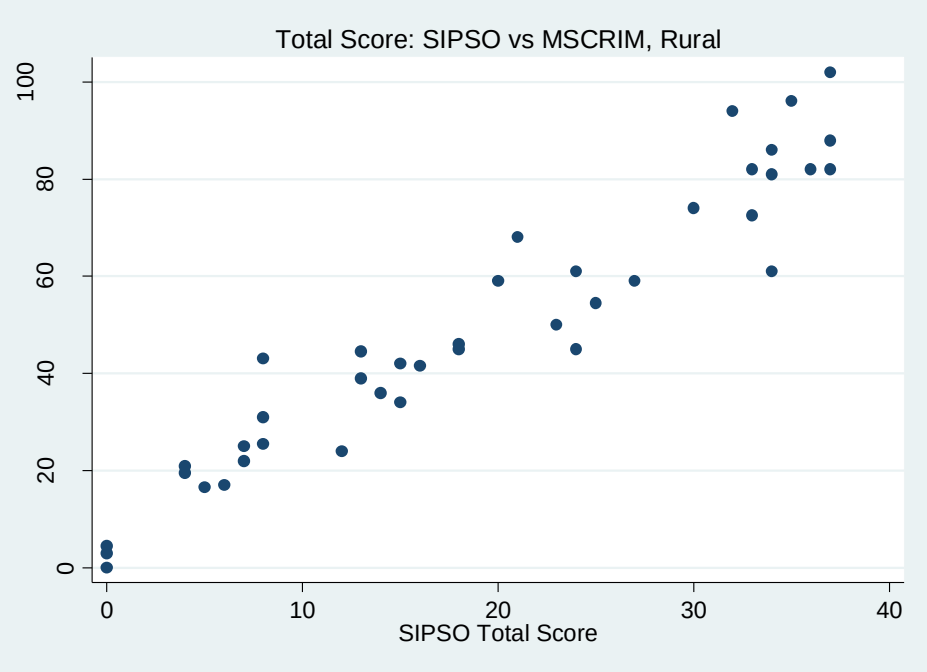


Figure 6.1: Scatter Plot of the MSCRIM (Rural Setting Version) Total Scores Against SIPSO Total Score (n = 40; r = 0.95; p = 0.001)

The figure below indicates the item mean scores of the MSCRIM (rural setting version) against those of the SIPSO.

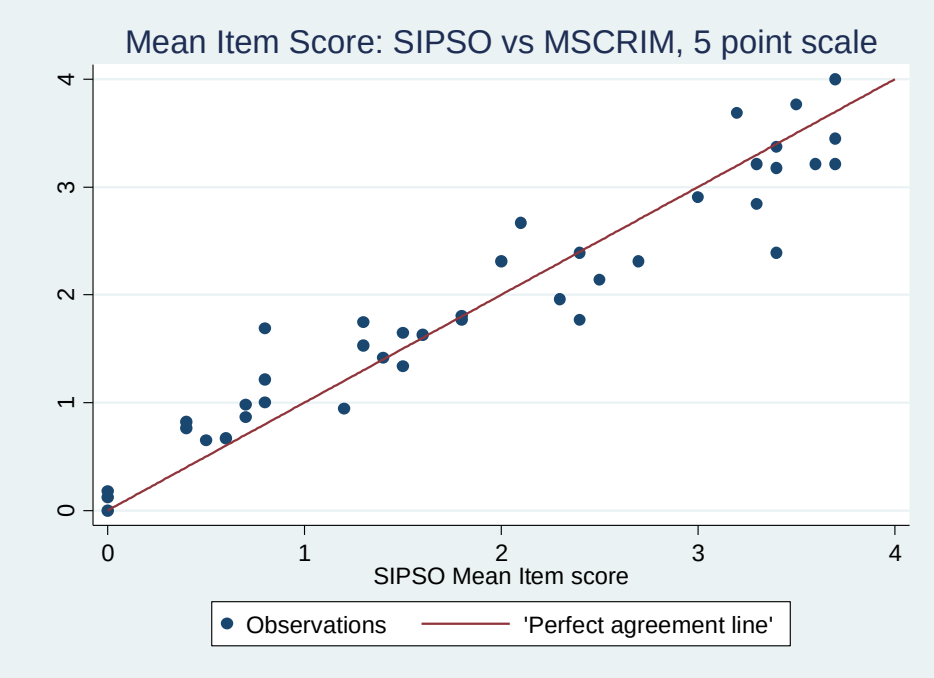


Figure 6.2: Scatter Plot of the MSCRIM (Rural Setting Version) Mean Item Scores Against SIPSO ean Item Scores (n = 40; r = 0.95; p = 0.001)

6.5.2.2 **The MSCRIM (urban setting version)**

The correlation between the total scores of the MSCRIM (urban setting version, 40 items) and the SIPSO (10 items) was r = 0.88; p= 0.0001 level (2-tailed). There was a very high correlation between the two outcomes.

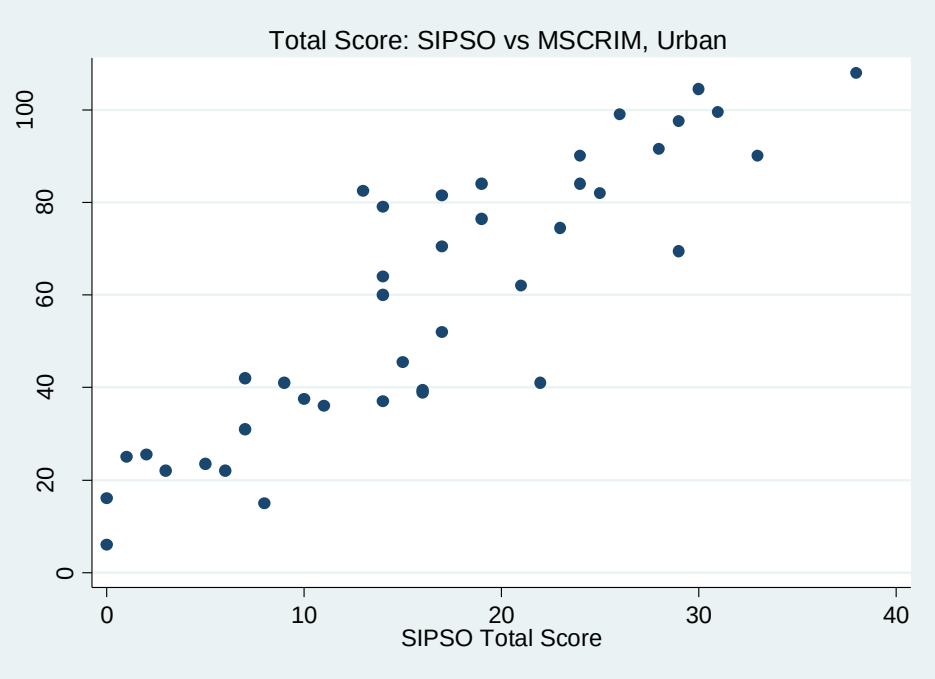


Figure 6.3: Scatter Plot of the MSCRIM (Urban Setting Version) Total Scores Against SIPSO Total Score (n=40; r = 0.88; p= 0.0001 level)

The figure below indicates the item mean score of the MSCRIM (urban setting version) against the item mean score of the SIPSO. The figure indicates that the MSCRIM has a high mean item scores as compared to the SIPSO.

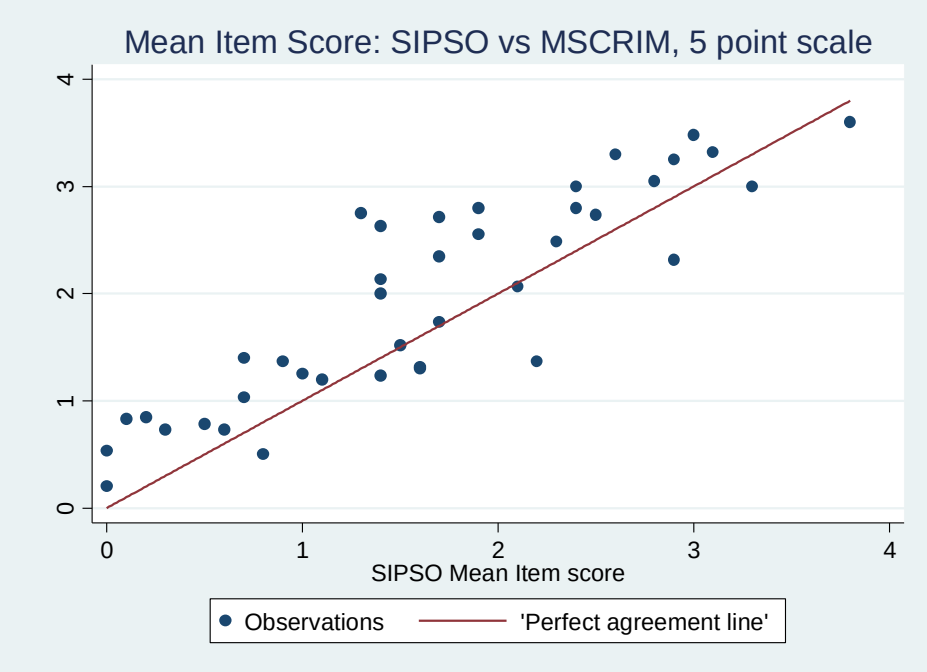


Figure 6.4: Scatter plot of the MSCRIM (urban setting version) mean item scores against SIPSO mean item scores (n=40; r = 0.88; p= 0.0001 level).

The section below discusses the results presented above.

6.6 DISCUSSION

Please note, only the items similarities and differences between the SIPSO and the MSCRIM (both versions) will be discussed in this Chapter (6) and the rest of the MSCRIM items (both version) will be discussed in Chapter 7, including the contextual differences between the MSCRIM and other measures.

6.6.1 The MSCRIM (Rural Setting Version)

There was a positive and high correlation between the total and the mean scores of the MSCRIM (rural setting version) and those of the SIPSO. These results indicate that the two outcome measures appear to be measuring the same construct. The reason for this high correlation can be attributed to the similarity of the items contained in both OM. Seven out of the 10 items contained in the SIPSO are similar to the MSCRIM (rural setting version) items in the various domains.

The MSCRIM (rural setting version) contains 34 items spread over six domains whereas the SIPSO has 10 items. The first SIPSO item establishes the difficulty in dressing. This item is contained in domain four of MSCRIM (rural setting version) and it also establishes the ability to

dress. Domain four of the MSCRIM (rural setting version) has other items that establish the patient's ability to do ADL and care for self. Recovery from stroke is often defined in terms of physical and task-oriented improvement (Duncan & Lai, 1997). Being able to dress is one of the meaningful activities of daily living that is essential to community reintegration.

The second and the fifth items of the SIPSO that are related to MSCRIM (rural setting version) assess the ability to move around all areas of the home and local neighbourhood. These items are closely related to the mobility domain of MSCRIM (rural setting version). This domain in the MSCRIM not only established the mobility around home but also around patients' yards and community. Ambulation is an important predictor of community reintegration (Dunsky et al., 2008).

The fourth item in the SIPSO assesses the difficulties associated with shopping and the ability to carry shopping bags. This item is related to an item contained in the first domain of the MSCRIM (rural setting version). This item establishes the ability to carry heavy objects like shopping bags.

Items seven, nine and 10 of the SIPSO are related to items contained in domain five of the MSCRIM (rural setting version). These items in the SIPSO assess the amount of communication and the frequency of visits to friends, whereas item 10 in the SIPSO assesses the feelings about the patient's appearance when out in public. In the MSCRIM (rural setting version), these items are all in the relationship or social interaction domain, they establish satisfaction with regards to communication, appearance and visitors.

The difference between the MSCRIM (rural setting version) and the 10 items SIPSO is that the MSCRIM (rural setting version) contains other items that are very context specific to the rural setting. For example in the first domain (home and family responsibilities); item four establishes the ability of the patient to collect firewood, chop wood and prepare a fire. Item eight in the MSCRIM assessess the ability to collect water from the river or communal tap. The ability to use the same transport that the patient used before the stroke as well as being able to work in the fields is a very important ability. All these items are necessary and specific to the issues that a patient with a stroke living in the rural areas of South Africa has to deal with on a daily basis.

The second domain of MSCRIM (rural setting version) specifically deals with social and community responsibilities of a person living in a rural area. These responsibilities get passed

down from one generation to the next and these responsibilities are learnt from childhood. For example in most rural areas in South Africa, family and community members still dig graves to bury the dead. Men living in the rural areas, are expected to be grave diggers, whilst women are expected to assist the family that is mourning with their house chores in the week leading up to the burial ceremony. This social and community responsibility is important for a person living in rural areas. The expectation is that when you have a person who has died in your family the community will assist you with the digging of the grave. The other items in the same domain establish the ability to be able to attend social clubs. Again, this is a very common activity in these poor socioeconomic areas. A group of people come together to save money for any kind of disaster, the expectation is both to attend the meeting on a monthly basis as well as contributing to the savings scheme.

Most patients in Study 1 (both settings) identified the role that religion and faith played in their recovery. Most patients felt that if they were able to go to church that would help them to get better sooner. This item was specifically included to tap this source of inspiration and hope, as part of community and social responsibility.

In conclusion, although the two OM were found to measure a similar construct, the MSCRIM (rural setting version) contains context specific items that were applicable to this rural setting and SIPSO does not contain these items, although the aim of both is to assess community reintegration following stroke. The SIPSO was developed as a self administered scale for a more educated UK population, whereas the MSCRIM was developed as an interviewer administered measure for patients living in poor socioeconomic urban and rural areas of SA.

6.6.2 **The MSCRIM (Urban Setting Version)**

In the urban setting similar results were obtained. The correlation between the total scores of the MSCRIM (the urban setting version) and the SIPSO was good and the correlation was high between the two outcomes. However, the MSCRIM (the urban setting version) has a higher mean item score compared to that of the SIPSO. Seven of the SIPSO items are contained in the MSCRIM (urban setting version), which is similar to the rural version.

The MSCRIM (urban version) contains 40 items spread in different domains. The first, second and fifth SIPSO items establish the difficulty in dressing, moving around all areas of the home and the local neighbourhood. These items are contained in the ADL and self care domain (one) of the MSCRIM (urban setting version).

The fourth item in the SIPSO assesses the difficulties associated with shopping and the ability to carry shopping bags. This item is related to two of the items contained in the two different domains of the MSCRIM (urban setting version), which are ADL and self care as well as home and family responsibilities.

Items seven, nine and 10 of the SIPSO are related to items contained in domain one (ADL and self care) and domain two (social interactions/relationships) of the MSCRIM (urban setting version). These items in the SIPSO assess the amount of communication and the frequency of visits to friends, whereas item 10 in the SIPSO assesses the feelings about the patient's appearance when out in public.

Similar arguments given for the items in the rural setting version (MSCRIM) can be used to account for the contextual differences between the MSCRIM (urban setting version) and the SIPSO. Items contained in domain two of the MSCRIM (urban setting version) establish the social interaction/relationships in a community. For example, item four assesses the ability to carry out some community roles. A man living in the urban area although not expected to dig graves, must assist with manual jobs like pitching a tent for the funeral attendees, whilst women are expected to assist the family that is mourning with house chores. These social and community responsibilities items are important for a person living in an urban area. The expectation is that when you have a person dying in your family, the community will assist in some way.

The other items in the same domain assess the ability to be able to attend social clubs ('society"); a social club is a social organisation made up of 10 to 20 people, this group of people come together to save money for any kinds of disaster. The expectation is for one to attend meetings on a monthly basis as well as contributing to savings schemes. The main aim of these social clubs is to collectively save money and support each other in times of disasters like death in the family. It is expected of a person who belongs to such a social club to attend a physical face to face meeting once in a month at a different location. This is a very common activity in poor socioeconomic areas such as Soweto and in Limpopo province.

Religion and faith were identified as major determinants to recovery by most patients in Study 1 (in both settings). The patients frequently stated church as a place from where their inspiration was drawn. Most patients felt that if they were able to go to church that would help them to get better sooner. This item is specifically included to cater for this source of inspiration and hope as part of community and social responsibility.

The last item in the urban setting version that is contextual is in domain four. The item assesses the assistance that family and friends give the patient. Most patients in this study were not working and not getting a government social grant either. Travelling to any place (health facilities included), where transport is required becomes a problem for them. The family normally assist with the travelling funds or in making a plan to move the patient from one area to the next. This assistance is reported to occur more in the urban areas. In the rural setting patients mostly receive home based care because of the vastness of the areas and inability to travel in the rural setting.

6.7 CONCLUSION

The aim of this phase (three) of study 2 was to obtain empirical data to validate the construct of the MSCRIM by comparing it with the SIPSO.

- A very high correlation was found between the MSCRIM (urban and rural setting version) and the SIPSO.
- The positive correlation is an indication that the two outcome measures were measuring a similar construct, community reintegration after stroke. However, MSCRIM (both versions) contains items that are contextually specific to black patients with a stroke living in poor socioeconomic urban and rural areas in South Africa.

The results for the whole study are discussed in the next chapter (7)

CHAPTER 7

7. DISCUSSION OF THE WHOLE STUDY

7.1 INTRODUCTION

This chapter will discuss the findings that were obtained from the whole study. The discussion will include the following sections: conceptualising community reintegration from patients' as well as caregivers' perspectives, development of the preliminary outcome measure, the whole validation process and lastly, the chapter will discuss the application of the ICF as a framework for this study in relation to the MSCRIM.

The overall aim of the whole study was to develop, validate and test the reliability of an interview- administered outcome measure to assess community reintegration following stroke of people living in poor socioeconomic rural and urban communities in South Africa.

7.2 DISCUSSION

7.2.1 Conceptualising Community Reintegration from the Perspective of the Participants

The first objective of Study 1 was to conceptualise community reintegration from the perspective of patients with a stroke and their caregivers. The experience of living with stroke as told by the participants in this study was not a positive one. The conceptualisation of community reintegration was derived from the patients' experiences described in study 1. The seven themes emerging from Study 1 suggest a depressing experience. The conceptualisation of community reintegration according to the patients is **multidimensional in nature**. The conceptualisation phrased in a positive manner, incorporates the ability to move around in one's home and community, not being isolated, without having roles reversed and identity loss. The person should be able to work to sustain his/her life and/or family and not lose hope.

The first dimension emerging from the conceptualisation is the ability to move around in different settings and environments. Walking is an important human activity which enables us to be productive and participative members of a community (Ada et al., 2009). Community ambulation is a meaningful outcome after stroke (Lord et al, 2004). Community ambulation has been broadly defined as locomotion outdoors to encompass activities such as visits to the supermarket, shopping mall; banks, social outings, vacation and pursuit of leisure activities (Lord et al, 2004). The patients in this study expressed their inability to move around as one of the factors that hindered their community reintegration. In this study, there were varying degrees of immobility as most patients were unable to move around in their homes whilst

others were not able to move around in their community. There were internal (personal) and external (environmental and contextual) factors that hindered the patients from moving around.

Some of the internal factors were related to the impairments that were brought about by the stroke such as muscle weakness, decreased range of motion, poor balance in different positions, reduced confidence to move and lack of assistive devices to aid in mobility. The reduction in the ability to walk resulted in major limitations in community participation. Hill et al., (1997) found that many individuals after stroke could not walk fast enough to do most of the activities in a community e.g. shopping; most patients in this study were not able to achieve this important task. The inability to move around made patients in this study dependent on others for ADL. As a result of the dependence, social relationships become very critical to survival for patients after a stroke and become of critical importance to their quality of life (Lynch et al, 2008).

Some of the external factors were related to environmental and contextual factors, such as the type of house that patients lived in (the houses were small and had uneven terrain outside) and in the community. Most roads were not tarred thus making mobility in such areas difficult. The other major environmental factors that hindered mobility were firstly, the lack of an efficient and available public transport system and secondly, the distance travelled from home to the nearest point where public transport could be accessed, the distance being even longer in the rural areas. This had a huge impact on patients' community mobility such as the inability to visit family and friends, to attend follow up appointments at the clinic or hospital and to participate in other community activities such as attending church or funerals.

The second dimension was social isolation; this dimension was closely related to the inability to move around. Patients in this study felt cut off from their world due to the inability to move around their homes and in the community. Social isolation is defined through self report of knowing fewer people well enough to visit their homes or to be visited (Boden-Albala et al, 2005). The resultant effect of social isolation for a person with stroke was a disruption of their social structures and networks. Additionally due to their immobility, and sometimes inability to express oneself verbally, it was very difficult for patients to get out and establish relationships. Furthermore, social isolation meant that patients were not being supported through their ordeal, an important factor that is strongly linked to recovery (Glass et al., 1993).

The third dimension central to the conceptualisation of community reintegration of a person with a stroke is the loss of the usual role within the family, community and society at large. This

loss of role is also described as loss of personal identity (Ellis-Hill and Horn, 2000) or change in personal characteristics (McKevitt et al., 2004). Salter et al, (2008) in a qualitative meta-synthesis study to define the experience of living with stroke, concluded that the loss of identity amongst patients with stroke is associated with the “enforced change in role”. All participants in the study expressed this loss of role, they had previously had a role to play in their family and community and now it was difficult to fulfil this role.

The fourth dimension is the loss of meaningful activities. With regard to the loss of meaningful activities of daily living, it is a widely accepted fact that stroke is among the leading causes of long-term disability. Many people who have had a stroke live with physical, psychological and functional limitations that have an impact on their daily activities and social roles (Dombovy et al., 1987). A number of people with stroke will not be able to resume their previous activities (Parker et al., 1997). Their participation in daily living and social roles will therefore be restricted, leading to handicap situations in various aspects of their lives (Desrosiers et al., 2006b). The patients in this study expressed their inability to perform tasks that were viewed to be important in their homes or community such as activities of daily living (ADL); getting up in the morning, bathing, dressing, cooking and eating. Most participants were not able to attend functions in the community such as funerals, social clubs, community meetings, burial society meetings and weddings. In both the urban and rural settings, there are certain expectations with regards to attendance of functions such as funerals e.g. women are expected to assist the family with house chores whilst men are expected to assist with the digging of the graves in rural areas. These are regarded as important and meaningful activities in most black rural and urban communities, and the loss of ability to undertake such activities could be considered in these societies to be a poor outcome of community reintegration.

The fifth dimension is the threat to livelihood or existence, a feeling that was strongly expressed by patients with stroke in this study. The sentiment was brought on by the fact the stroke is an incapacitating condition and thus participants were unable to work and thus provide for their family. For some participants it meant that they were unable to finish a training programme which would then enable them to get a job and earn a decent living. Despite some participants having a better prognosis, many participants still reported difficulties in returning to work or training programmes.

The last dimension is loss of hope. It is a common phenomenon for stroke survivors to express feelings of despair and helplessness after a stroke (Pilkington, 1999). The concept of hope can be characterized by expression of uncertain feelings of the future. Most patients in

this study expressed feelings of hopelessness to the new situation they were facing. The participants often expressed the sentiments such as not being sure that there was a cure for stroke, not wanting to be a burden to their family, uncertainness of what the future held for them and wanting to die. The presence of these feelings can affect the patient's community reintegration. On a positive note, patients in this study drew strength from their faith and religion to foster hope.

Wood-Dauphinee et al., (1988: 583-590) defined *"integration as the organization of organic, psychological, and social traits and tendencies of an individual into a harmonious whole. Therefore reintegration to normal living could mean the reorganization of physical, psychological and social characteristics so that the individual can resume well-adjusted living after an incapacitating illness or trauma like stroke"*. Similarly Trigg and Wood (2000: 288-299) defined community or social reintegration "*as the ability of an individual to live in the most natural environment possible, interact with a wide variety of people, and take part in the usual activities of society".* The above experiences were documented from patients living with a stroke in high income countries (McKevitt et al., 2004; Lynch et al., 2008) but very little was known about the experiences of patients living in poor socioeconomic rural and urban areas in low income countries. This study has attempted to document experiences of patients living in poor/low socioeconomic areas such as those found in SA. In summary, based on this reintegration back into the community the same basic wishes and experience are the same no matter where you live or who you are but may differ depending on the context for example rural versus urban areas, socioeconomic status (poverty), lack of basic services and culture (Schneider et al, 2008).

The information gained from the conceptualisation of community reintegration was used to develop the outcome measure. The next section discusses the development of this outcome measure.

7.2.2 **Development of the Preliminary Outcome Measure**

From the seven themes that emerged from study 1, 67 items were generated for the questionnaire using statements based on what the participants said in the interviews. This document was the preliminary questionnaire used in the validation phases. Trigg and Wood (1999) in the development of the SIPSO had a total of 97 items developed from the interview data with patients.

These 67 items in this study were categorised under 11 domains. The 11 domains covered all the areas of how patients in this study conceptualised community reintegration and appeared to be similar to domains identified in previous studies namely, ***ADL and personal care*** (Wood-Dauphinee et al,1988; Duncan et al, 2001), ***home and family responsibility*** (Wood-Dauphinee et al, 1988; Willer et al, 1994; Trigg and Wood, 2000; Duncan et al, 2001), and ***community and social responsibility*** (Wood-Dauphinee et al, 1988; Willer et al, 1994; Trigg and Wood, 2000; Van Brackel et al, 2006a).

The domains also covered ***relationships*** (Wood-Dauphinee et al, 1988; Trigg and Wood, 2000; Duncan et al, 2001; McColl et al, 2001; Van Brackel et al, 2006a), ***travel and transport issues*** (Wood-Dauphinee et al, 1988; Duncan et al, 2001) as well as ***leisure and recreation*** (Wood-Dauphinee et al, 1988; Willer et al, 1994; Trigg and Wood, 2000; Duncan et al, 2001; McColl et al, 2001; Van Brackel et al, 2006a). The last domains assess ***work/education issues*** (Willer et al, 1994; Duncan et al, 2001; McColl et al, 2001, Van Brackel et al, 2006a) and ***psychological adjustment/coping mechanisms*** (Wood-Dauphinee et al, 1988; Duncan et al, 2001).

The next section discusses the validation process of the preliminary outcome measure and the items contained in the MSCRIM (both versions).

7.2.3 Validation Studies

Validation is a very important step in the development of an outcome measure. In this process it is especially important to include the opinions of professional experts as well as people who are affected by the condition being studied for example Trigg and Wood (1999) included health professional experts and patients in the development of the SIPSO to ensure face and content validity. The face and content validation of the outcome measure developed in this study was established through several steps. Three rounds of the Delphi technique with a group of rehabilitation experts and two meetings of a nominal group of patients who had had a stroke were conducted. Furthermore, these steps assisted in reducing the number of items in the measure.

FA and internal consistency statistics have been used in the development of outcome measures (Cheing et al., 2010). Scale or test developers start with a large number of individual scale items and questions and, by using factor analytic techniques, they refine and reduce these items to form a smaller number of coherent subscales (SSPS, 2007). Internal consistency helps in identifying items that are not correlating with the others in a scale, in other

words, items that would reduce the scale's reliability. The internal consistency for both the rural and the urban setting versions of the MSCRIM was (Cronbach alpha = 0.95) indicating that the homogeneity of the items contained in each outcome measure was excellent. This finding is similar to some of the OMs reviewed for example Kersten et al., (2004) reported that the SIPSO had a very good internal consistency (Cronbach alpha = 0.91). Similarly, (Duncan et al. 1999) concluded that each of the eight domains in the SIS approached the standard of 0.9 alpha coefficients meaning the items contained in the scale are homogenous. In using these two statistical techniques in this study, the original 67 items were reduced to 46. The items that were excluded would have not been recognised by observational scrutiny by experts, patients or the researcher, as all these people thought that all items assessed community reintegration. It required statistical analysis to identify redundant items.

To further demonstrate the validity of an instrument, one needs empirical evidence to show that the tool or instrument is measuring what it is intended to measure. The psychometric properties of the developed measure were then compared to an existing outcome measure, the SIPSO. A very high correlation ($r = 0.95$ $p = 0.0001$ for the rural version OM and $r = 0.88$, $p = 0.0001$ for the urban version of the OM) was found between the MSCRIM and the SIPSO. The positive and high correlation is an indication that the two outcome measures were measuring a similar construct, community reintegration after stroke. However, MSCRIM (both versions) contains items that are contextually specific to black patients with a stroke living in poor socioeconomic urban and rural areas in South Africa.

The outcome of the validation process, was two versions of the outcome measure (now known as the MSCRIM) an urban version and a rural version with each version containing different domains and items. The items contained in both versions are discussed below.

7.2.3.1 **Items contained in the MSCRIM (both versions)**

According to the online English Oxford dictionary, the word context refers to the surroundings, circumstances, personal factors (culture, level of education and spoken language), environment, background, or setting which determine, specify, or clarify the meaning of an event. Taking context into consideration is extremely important when thinking about community reintegration following a stroke. The contextual issues that specifically apply to the population in this study are (1) many Black South Africans are from a poor background, (2) many are illiterate, (3) a host of different languages are spoken, (4) there are a number of different cultural beliefs and practices, (5) people live in different circumstance from hutted villages to small houses with outside toilets (6) in many of the areas where black South African people

live most of the roads are not tarred and (7) many people live far from the main roads, where public transport can be accessed. The items contained in the MSCRIM took these contextual issues into account and are discussed below.

Being able to perform ADL and self care activities is central to and an important aspect of community reintegration. The inability to perform ADLs may lead to dependence as reported in a study by Hale et al, (1999). Therefore, the following items were included under the ADL and self care domain of both versions of the MSCRIM: **are you able to wash, dress, feed yourself, drink water from a glass or cup, and pour water into the kettle**. Most OMs of community have included the ADLs such as the ability to bath, dress, feed and toilet (Wood-Dauphinee et al, 1988; Williams et al, 1999; Trigg and Wood, 2000; Duncan et al, 2001). In addition to the above ADL, the MSCRIM also included an additional ADL item in both versions **"are you able to get up and out of bed in the morning".** This item was included because both the experts and the patients viewed it as being an important ADL and the first activity following stroke that patients must be able to do.

Mobility and the physical environment in which patients live plays a vital role in community reintegration following stroke, hence the following items were included in both the versions of the MSCRIM to assess this activity: **are you able to move around uneven and hilly areas"** and **are you able to move around your home; yard and lastly your community**. These items were included because in SA people live in different circumstances hutted villages, tin shacks, and small brick and mortar houses with outside toilets. In addition, many of the areas the roads are not tarred, and the roads or paths are uneven and steep especially in the rural areas. Although other existing measures (Whiteneck et al, 1992; Harwood et al, 1994; Williams et al, 1999; McColl et al, 2001; Duncan et al, 2001; Van Brackel et al, 2006) have included some of these items, they use terminology and concepts that would be foreign to the patients in this study such as are you able to walk around a block from your house (Akinpelu et al., 2007).

Travelling in SA can also be expensive for a person with disability in both rural and urban areas; most of the patients are not working and are not getting a social disability government grant, and as mentioned previously the taxis can charge more for people with disability (as they are slow in getting on and off the transport and their mobility assistive devices take up room). Hence, the inclusion of the following items **"are you able to use the same transport that you used before the stroke" and "are your friends and family assisting you with your travelling needs".** Wood-Dauphinee et al, (1988) included a similar item in their RNLI

known as “distant mobility”, referring to being able to take distance trips out of town as necessary. Similarly, Whiteneck et al, (1992) included this item as “ability to move about effectively in ones surroundings”. In the SIPSO, the physical difficulties associated with mobility are assessed (Trigg and Wood, 2000). On the contrary, Williams et al, (1999) referred to mobility as the “ability to maintain ones balance in all positions when moving around”. None of these OMs however included an item that looked at the logistics of travelling, such as the expense of it, hence the inclusion of these items in the two versions of the MSCRIM.

Home and family responsibilities are also important to community reintegration of a person with a stroke and the following items were included in both versions of the MSCRIM under this domain: **“Are you able to clean your house”** and **“are you able to cook and prepare meals for your family”.** It should be noted that the preparation of meals for most people especially in the rural areas is difficult as most families are still using open fires on which to cook. Once cooking is done, dishes, pots and other utensils need to be washed hence the inclusion of this item **“are you able to clean the area and utensils used for preparing meals”.**

Most people do not have washing machines in their homes; hand wash is the most commonly used method in most households hence the item **“are you able to wash the clothes and hang them on a washing line or dry them the way you have always done”**. Method for drying wet washing can vary depending on location, if some rural people still wash clothes in river following which the clothes are spread on the grass or rocks to dry. However if the washing was done at home where washing lines are available then the clothes will have to be hung on the line to dry. Electric clothes driers are not used. As part of home and family responsibilities, the specific activities **“are you able to collect firewood, chop and prepare fire”** are contained in the rural version of MSCRIM, because most people in the rural areas do not have electricity, so the use of wood for making fire is still the method used to cook and warm the house.

As a result of the FA, two items ended up in the urban version of the MSCRIM as extended family responsibilities. The first item **“are you able to take care of your livestock”** was included as most people in the urban areas have domesticated animals that need to be looked after and there are no family that can take over this role, whereas in the rural areas members of the extended family will take over the care of animals. The second item contained in the urban version of the MSCRIM is **“are you able to teach your children home keeping tasks”.** The reason for inclusion of this item is that the poor circumstances of the people would

not allow them to have a maid to assist with home keeping tasks and therefore teaching children some of these housekeeping tasks is a necessity. Please note, in developed countries, people do not have maids but they have electrical appliances to help with the load, whereas in this setting the children need to help in the absence of these appliances.

Being able to take care of one's environment is another important activity so the following item was included **"are you able to take care of your garden or fields".** Many patients in this study, especially in the rural areas, have fields or garden to take care of. The fields help with provision of inexpensive food. Being able to take care of these gardens or fields is another way of assessing community reintegration in the context of these patients.

The last two items included under the domain of home and family responsibilities were the "**ability to fetch water from outside water taps or from the river"**. Some people do not have water taps in the house but have to collect water from taps located outside, whilst some people have to collect water from the nearest river. The last item under this domain assesses the patient's ability **to carry heavy objects for example shopping bags**. Wood-Dauphinee et al, (1988) included similar items under the domain of "family roles", however, the item only asked about the patient's ability to assume these roles not whether they can actually do them, as the MSCRIM asks. Similarly Willer et al, (1994) have included this domain but termed it as "home integration", which referred to the patient's ability to do household chores, including looking after self and children. Williams et al, (1999) in their SS-QOL have this domain as "family responsibility" but refers to the ability to do shopping, pay bills and do the banking.

The other domain included in both versions of the MSCRIM is "community and social responsibilities". Community and social responsibilities are taken very seriously in low socioeconomic rural and urban areas of SA, where the majority of the people are black and poor. There is a common South African saying in Zulu, "Umumtu wu muntu nga bantu" meaning you are who you are because of other people. This saying is famously known in SA as "Ubuntu". In the context of patients living in poor socioeconomic areas of South Africa, there is a huge sense of community and social responsibilities that need to be carried out. The following items are included in both versions of the MSCRIM to assess this domain:

- **"are you able to attend social events such as funerals, parties and weddings";**
- **"are you able to attend burial societies, social clubs, community meetings";**
- **"are you able to carry out other community roles like digging of graves";**
- **"are you able to attend religious and spiritual related activities"**

In most rural areas in South Africa, family and community members still dig graves to bury the dead. As a man living in the rural areas, you are expected to be one of the grave diggers, whilst women are expected to assist the family that is mourning with their household chores in the week leading up to the burial ceremony. In the urban areas even though men are not expected to dig graves they do other chores like pitching a tent where people will be congregating during the funeral, whilst women do exactly the same as their rural counterparts. Attending a funeral is not just being there physically on the day of the actual burial but is seen as supporting the family in all aspects as they are preparing to bury their relative. The other items in the same domain establish the ability to be able to attend social clubs/burial societies. These are common activities in these poor socioeconomic areas. A group of people meet with the purpose of saving money for any kind of disaster. The expectation of belonging to these social clubs is to attend meetings in different locations on a monthly basis, as well as contributing to the savings scheme. The ICF (WHO, 2001) refers to this domain as community, social and civic life. The inclusion of these items is unique to the MSCRIM, as the other reviewed OM includes this domain in general terms, for example, are you able to attend social gatherings and not as specific as the items in the MSCRIM.

Leisure and recreation have been shown to be closely associated with life satisfaction are worthwhile and measurable goals of rehabilitation (Parker et al, 1997). The following items were included to cover leisure and recreation activities in both versions of the MSCRIM **“are you able to do an activity for self enjoyment or relaxation”** and **“are you able to get out of the house to go shopping in town or going out with friends or watch soccer matches at a stadium”.** Most leisure and recreational activities are universal, hence, this domain is included in all the OM that have been reviewed; however, one’s social and economical class largely determine the kind of leisure activities that are undertaken. In most low socioeconomic areas of SA, there are very few leisure activities available, especially in the rural areas. The MSCRIM has included the most common leisure activities that patients in these settings may relate to, for example being able to go to a stadium to watch soccer. In light of the low levels of education of the target population, the words “leisure or recreation” were not used as they would not be understood; instead the words “activities of self enjoyment or relaxation” were used.

As discussed previously social interactions and relationships form a major part of community reintegration. Socially isolated patients may be at particular risk for a poor outcome, in both function and QoL (Glass et al., 1993). Social support may be an important prognostic factor in

the recovery from stroke. With that in mind, the following items were included in the MSCRIM (both versions) to assess the level of satisfaction of the patients:

- **"how satisfied are you with your interactions with other people"**
- **"how satisfied are you with your appearance in public"**
- **"how satisfied are you with people visiting you or visiting others"**
- **"how satisfied are you with the help and support you receive from your family"**
- **"how satisfied are you with your ability to solve family and friends problems"**

In addition to the above, the following social interaction and relationship items are contained in the urban version but not in the rural version of the MSCRIM:

- **"how satisfied are you with your ability to physically assist someone"**
- **"are you able to remember things told and events easily"**
- **"are you able to make decisions regarding your life and family issues"**
- **"are you able to do a physical activity such as playing any sport"**

The following item is contained in the rural version of the MSCRIM in the social interaction and relationship domain in addition to the five items presented above:

- **"how satisfied are with your communication with family and people around you"**

The OMs reviewed include some of these items but not as measures of the level of satisfaction of patients. For example, in the RNLI (Wood-Dauphinee et al, 1988), there is an item that refers to personal relationships, which asks how comfortable one is with personal relationships. Another item in the same index is on presentation of self to others, which refers to how comfortable one is with self when one is in the company of others. Similarly in the SIPSO (Trigg and Wood, 2000) the item on presentation in public is presented in the same way as in the RNLI. The SS-QOL (Williams et al, 1999) and SIS (Duncan et al, 2001), have included items that are related to memory i.e. the ability to remember things and events. The uniqueness with regards to the MSCRIM is that these items are presented as a measure of satisfaction and secondly a measure of the ability of a person to make decisions regarding his life and that of family. The MSCRIM also takes into account the ability to communicate, not only with the immediate family, but also with other people in the community. Above all, in the spirit of "Ubuntu", the MSCRIM has included an item on being able to physically assist others.

Returning to work or school for people with stroke may contribute significantly to their life satisfaction, well being, self-worth and social identity, giving them an opportunity to maintain independence as far as physically possible with the income generated through employment (Wolfenden and Grace, 2009; Hsieh and Lee, 1997). In light of return to work or school the

following items were included in the MSCRIM (both versions), **"are you able to go to work"** and **"are you able to attend school or training programmes in and out of your community".** All OMs reviewed have included an item on return to work, the MSCRIM has, over and above, that included return to school/university because in the context of SA's epidemiological transition (due to HIV and AIDS) there are more young patients who are affected by stroke (Connor et al, 2004, Mudzi, 2009). Return to school or university for these young people may be a good indicator of successful community reintegration.

The section below discusses how the ICF was used as a framework for the development of this outcome measure and how items of the MSCRIM fit into the ICF.

7.2.4 The Application of ICF as a Framework for this Study in Relation to the MSCRIM

The WHO ICF (2001) provides multi-dimensional framework for health and disability suited to the classification and development of a new outcome measures/instruments (Salter et al., 2005c). Outcomes may be measured at any of the ICF levels/domains/dimensions. Participation restriction happens when an individual is unable to carry out his/her tasks or responsibilities due to a disease or illness. The restriction may not be due to reduced body structure and function only but may also be due to the environmental and/or personal factors referred to as contextual factors in the ICF. Participation is a relatively recent concept that is not clearly understood nor measured yet. This is one area of the ICF that deserves much more attention as increasingly; participation is considered a pivotal outcome of successful rehabilitation (Desrosiers, 2005).

Many studies have used the ICF as the framework for the development of outcome measures (Harwood et al., 1994; Hsieh et al., 2000; Mellick, 2000; Resnik et al., 2009). This study also used the ICF as a framework for the development of the outcome measure to assess the level of participation i.e. community reintegration after stroke. The table below illustrates how the domains and items of the MSCRIM fit in the framework of the activity and participation levels/domains/dimensions of ICF.

Table 7.1: The MSCRIM domains and items classified by domain of activities and participation ICF

Activities and Participation (ICF Chapters and Subcategories)	MSCRIM (urban) domains and items:	MSCRIM (rural) domains and items
1. Learning and applying knowledge		
d155 Acquiring skill	Domain 6 item 2	Domain 6 item 2
d175 Solving a problem	Domain 4 item 3	Domain 5 item 7
d177 Making decisions	Domain 4 item 6	
2. General task demand	Domain 1 items 1-16; Domain 2 items 1-6	Domain 1 items 1-9
d230 Carrying out daily routine	Domain 3 items 1-5	Domain 4 1-6
3. Communication		
d330 Speaking	Domain 2 item 7	Domain 5 items 3-4
d350 Conversation	Domain 2 item 7	
4. Mobility		
d430 Lifting and carrying	Domain 1 item 12	Domain 1 item 9
d450-d469 Walking and moving	Domain 1 items 7-11, 13	Domain 3 items 2-5
d470 Using transportation	Domain item 14, 13	Domain 1 item 10
d475 Driving	Domain item 14	Domain 1 item 10
5. Self care		
d510 Washing oneself		
d530 Toileting		Domain 4 items 1-5
d540 Dressing	Domain 1 items 2-6	
d550 Feeding		
d560 Drinking		
6. Domestic life		
d630 Preparing meals	Domain 3 items 2, 3	Domain 1 items 4-5
d640 Doing house chores	Domain 3 items 1-7, Domain items 1-2	Domain 1 items 1-9
d649 Household tasks	Domain 3 items 1-7	Domain 1 items 1-9
d660 Assisting others	Domain 3 item 7	
7. Interpersonal interactions and relationships		
d710 Basic interpersonal relationships	Domain 2 items 2-6, Domain 4 items 1-4	Domain 5 items 1-5
8. Major life		
d810 Informal education	Domain 6 item 2	Domain 6 item 2
d820 School education	Domain 6 item 2	Domain 6 item 2
d830 Higher education	Domain 6 item 2	Domain 6 item 2
d850 Remunerative employment	Domain 6 item 1	Domain 6 item 1
d855 Non-remunerative employment	Domain 6 item 1	Domain 6 item 1
9. Community, social and civic life		
d910 Community life	Domain 2 items 2-5	Domain 2 items 1-4
d920 Recreation and leisure	Domain 1 item 15	Domain 4 item 6
d930 Religion and spirituality	Domain 2 item 5	Domain 2 item 4
10. Environmental Factors: Support and relationship		
e310 Immediate family	Domain 4 item 2	Domain 5 items 5-6
e315 Extended family	Domain 5 item 2	Domain 5 item 1
e320 Friends	Domain 4 item 1	Domain 5 items 1, 5

7.3 CONCLUSION

The major findings, conclusions and the recommendations from the whole study (1 and 2) are highlighted in the next chapter (8).

CHAPTER 8

8. CONCLUSION

8.1 INTRODUCTION

This chapter summarises the findings from all the studies with particular reference to the thesis's overall aim and objectives. The chapter also provides recommendations for future research.

The overall aim of this study was to develop, validate and test the reliability of an interviewer-administered outcome measure to assess community reintegration following stroke for people living in poor rural and urban communities of SA. The overall aim was achieved through several objectives and processes namely:

1. Conceptualising community reintegration from the perspective of individuals who have had a stroke and their caregivers in order to develop and construct the outcome measure. This was achieved via semi-structured interviews conducted in urban and rural areas.
2. Developing and constructing the items of the outcome measure using the information gained from the interviews and review of the literature.
3. Validating the outcome measure and reducing the number of item in it through a Delphi technique with neurological and community based rehabilitation experts and a nominal group technique with patients and caregivers in both settings (rural and urban),
4. Reducing and regrouping of items using factor analysis.
5. Establishing the reliability of the outcome measure through internal consistency (Cronbach alpha).
6. Establishing construct validity (correlation) by comparing the MSCRIM with the SIPSO.

The result of these processes was the development of MSCRIM (the urban and the rural version). The main results of the study and the two versions of MSCRIM are presented below:

8.2 CONCLUSION OF THE MAIN RESULTS OF THE STUDY

The following conclusions are drawn from this thesis are:

- Community reintegration was conceptualised in this study by including the following factors "*the ability to move around in one's home and community, of not being isolated without*

having one's roles reversed and identity loss. The person should be able to work to sustain his/her life and not lose hope".

- The name of this outcome measure as suggested by the experts is the Maleka Stroke Community Reintegration Measure (MSCRIM) and has two versions the rural and the urban versions.
- The MSCRIM was developed based on the perspective of patients, their caregivers, health professional experts and with statistical advice from a statistician.
- The MSCRIM (both versions) was found to have sound factor structure and excellent internal consistency (0.95 for both versions).
- In comparing the MSCRIM with the SIPSO a very high correlation was found ($r = 0.95$ $p = 0.0001$ for the rural version OM and $r = 0.88$, $p = 0.0001$ for the urban version of the OM).
- Both versions of the MSCRIM are therefore considered to be valid and reliable measures to assess community reintegration following stroke for patients living in poor socioeconomic rural and urban communities of South Africa.
- The MSCRIM (both versions) is available in the following languages: Sesotho, IsiZulu, English, TshiVenda and XiTsonga.
- The MSCRIM (both versions) is interviewer administered and is easy to administer, very little training is required in its administration. It takes 15 to 20 minutes to administer.

The features of the two versions of the MSCRIM are outlined below:

Title of the OM: Maleka Stroke Community Reintegration Measure (MSCRIM).

The Demographic data: The demographic data of the participant will be on the first page of the MSCRIM (see Appendix 8.1).

Administration of the Measure: The MSCRIM will be interview administered therefore; items/statements/questions will be read out to patients from various domains and the patients needs to respond appropriately.

The instructions to the assessor: See Appendix 8.2

The instructions to the patients: See Appendix 8.3

The MSCRIM (The rural setting version):

Domain 1: Home and Family Responsibilities

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?				
2 Are you able to work in your garden or fields?				
3 Are you able to collect firewood, chop and prepare fire?				
4 Are you able to cook and prepare meals for your family?				
5 Are you able to clean the area and utensils used for preparing meals?				
6 Are you able to wash the clothes?				
7 Are you able to hang the clothes on a washing line or are you able to dry your clothes the way you have always done?				
8 Are you able to collect water from the river/communal tap?				
9 Are you able to carry heavy object(s) for example shopping bags (2-3)?				
10 Are you able to use the same transport you used before the stroke?				

Domain 2: Community and social responsibilities

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to attend social events in your community such as funerals, parties or weddings?				
2 Are you able to attend burial society, social clubs meetings and other structures meeting or meetings called by the chief/councilor in your community?				
3 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregants,?				
4 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?				

Domain 3: Independence (Mobility)

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to pour water into a kettle/ basin?				
2 Are you able to move around uneven/ hilly areas?				
3 Are you able to move around in your home?				
4 Are you able to move around in your yard?				
5 Are you able to move around in your community?				

Domain 4: ADL and Self care

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to get up and out of bed in the morning?				
2 Are you able to wash yourself?				
3 Are you able to dress yourself?				
4 Are you able to feed yourself?				
5 Are you able to drink from a cup or glass?				
6 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?				

Domain 5: Relationship

Item	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)
1 How satisfied are you with your interaction with other people?			
2 How satisfied are you with your appearance in public?			
3 How satisfied are you with your communication with family?			
4 How satisfied are you with your communication with people around you?			
5 How satisfied are you with people visiting you or your visiting others?			
6 How satisfied are you with help and support that you receive from your family and friends?			
7 How satisfied are you with your ability to solve family and friend’s problems			

Domain 6: Work and Education

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to go back to work (paid or volunteer)?				
2 Are you able to attend school or training programmes (including adult education) in or out of your community?				

The MSCRIM (The urban setting version):

Domain 1: ADL and Self Care

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to get up and out of bed in the morning?				
2 Are you able to pour water into a kettle/basin?				
3 Are you able to wash yourself?				
4 Are you able to dress yourself?				
5 Are you able to feed yourself?				
6 Are you able to drink from a cup or glass?				
7 Are you able to move around uneven/hilly areas?				
8 Are you able to move around in your home?				
9 Are you able to move around in your yard?				
10 Are you able to move around in your community?				
11 Are you able to collect water from the river/communal tap?				
12 Are you able to carry heavy object(s) for example shopping bags (2-3)?				
13 Are you able to get to the clinic/hospital to collect your medication or for rehabilitation/nursing/ medical help?				
14 Are you able to use the same transport you used before the stroke?				
15 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?				
16 Are you able to get out of the house to go shopping in town or going out with friends or watch a soccer match at a stadium.				

Domain 2: Social Interactions and Relationship

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to work in your garden or fields?				
2 Are you able to attend social events in your community such as funerals, parties or weddings?				
3 Are you able to attend burial society, social clubs meetings and other structures meeting or meetings called by the chief/councilor in your community?				
4 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregants,?				
5 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?				
6 Are you able to do a physical activity such as playing any sport?				
7 How satisfied are you with your interaction with other people?	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)	

Domain 3: Home/Family Responsibilities and Appearance

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?				
2 Are you able to cook and prepare meals for your family?				
3 Are you able to clean the area and utensils used for preparing meals?				
4 Are you able to wash the clothes?				
5 Are you able to hang the clothes on a washing line or are you able to dry your clothes the way you have always done?				
6 How satisfied are you with your appearance in public?	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)	
7 How satisfied are you with your ability to physically assist someone?	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)	

Domain 4: Social Interactions

1 How satisfied are you with your visiting other people and them visiting you?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)
2 How satisfied are you with help and support that you receive from your family and friends?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)
3 How satisfied are you with your ability to solve family and friend's problems	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)
4 Are your friends and family assisting you with your travelling needs?	No (0)	Yes, but rarely (1)	Yes, sometimes (2)	Yes, always (3)
5 Are you able to easily remember things told and events?	Not at all (0)		To some extent (1)	To a full extent (2)
6 Are you able to make decisions regarding your life and family issues?	Not at all (0)		To some extent (1)	To a full extent (2)

Domain 5: Extended Family Responsibilities

Items	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to take care of your livestock (if you have) e.g. feed your dogs or herd/tend your cattle/ goats, including milking?				
2 Are you able to teach children home keeping tasks e.g. cultural/traditional cooking, and mudding with cow dung?				

Domain 6: Work and Education

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to go back to work (paid or volunteer)?				
2 Are you able to attend school or training programmes (including adult education) in or out of your community?				

Interpretation of the score and feedback to the patient and caregiver:

The total score of MSCRIM (rural version) is 95 and for the urban version is 112. Once all the domains have been scored, all points are added and multiplied by 100% to get the final/overall score. The overall score will be used to determine the patient's level of community reintegration on the scale below. Lastly, the patient will be given feedback by the therapist administering the measure.

Cut off points:

- 80% and above means full reintegration
- 79%-60% moderate reintegration
- 59%-41% minimal reintegration
- 40%-0% no reintegration

The higher the overall score the more integrated the patient is in the community and vice versa, the lower the overall score the more poorly integrated the patient is in the community.

8.3 RECOMMENDATIONS

The recommendations for clinicians as well as future research are listed below.

8.3.1 For the Clinicians

In order for clinicians/therapists to holistically manage and improve patient's reintegration into a community, they must

- Be aware of long term issues associated with community reintegration following stroke such as loss of hope as this has been proven to lead to depression and further isolation for patients with ultimate poor reintegration.
- The therapists need to assess and be aware of the activity limitations and participation restrictions as outlined in the outcome (MSCRIM) and develop appropriate intervention rehabilitation strategies to fully reintegrate the patients into their homes and community.
- Use the outcome measure in a clinical setting as this will lead to identification of issues related to the psychometric properties of the outcome measure.

8.3.2 **For Further Research**

In order to further refine the psychometric properties of the MSCRIM the following are recommended

- To establish the stability or reproducibility of the outcome measure on a larger sample i.e. test-retest reliability.
- To test on the different sub-types of stroke and age groups in order to determine its sensitivity.
- To test the responsiveness of the MSCRIM particularly with longitudinal studies.
- To test on other people with physical disabilities living in the same socio-cultural communities in South Africa.

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APPENDIX 1.1

CHAPTER 1 APPENDICES: ETHICAL CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Maleka

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M070816**
PROJECT	Development of an Outcome Measure to Assess Community Reintegration after Stroke
INVESTIGATORS	Mr MED Maleka
DEPARTMENT	Department of Physiotherapy
DATE CONSIDERED	07.08.31
DECISION OF THE COMMITTEE*	APPROVED UNCONDITIONALLY

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
HREC (Medical)
Co-Chair
2007 -10- 15

DATE 07.10.04 **CHAIRPERSON** .....
(Professors PE Cleaton-Jones, A Dhai, M Vorster, C Feldman, A Woodiwiss)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof A Stewart

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX 1.2

LETTER OF APPROVAL FROM THE LIMPOPO PROVINCIAL HEALTH AUTHORITY

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT

Enquiries: Malomane EL

Ref: 4/2/2

17 April, 2008

Mr MED Maleka
University of Witwatersrand
Dear **Mr MED Maleka**

"The development of an outcome measure to assess community reintegration after stroke for patients living in poor socioeconomic urban and rural communities '

- Permission is hereby granted to **Mr MED Maleka** to conduct a study as mentioned above
- The Department of Health and Social Development will expect a copy of the completed research for its own resource centre after completion of the study.
- The researcher is expected to avoid disrupting services in the course of his study
- The Researcher/s should be prepared to assist in interpretation and implementation of the recommendations where possible
- The Institution management where the study is being conducted should be made aware of this,
- A copy of the permission letter can be forwarded to Management of the Institutions concerned

HEAD OF DEPARTMENT
HEALTH AND SOCIAL DEVELOPMENT
LIMPOPO PROVINCE

Private Bag X9302 Polokwane
18 College Str., Polokwane 0700 • Tel: 015 293 6000 • Fax: 015 293 6211 • Website: http/www.limpopo.gov.za

APPENDIX 1.3

LETTER OF APPROVAL FROM THE GAUTENG PROVINCIAL HEALTH AUTHORITY

Department of Health
Lefapha la Maphelo
Departement van Gesondheid
Umnyango wezeMpilo
JHB-WEST RAND REGION
JHB METRO DISTRICT

Enq. O.A.Memee
Tel 011 694 3836
Fax 694 3825

16th January, 2008

TO: FACILITY MANAGERS OF CHIAWELO, MOFOLO, ALEXANDRA, AND ZOLA

FROM: O.A. Memee

DATE: 16/01/2008

SUBJECT: APPROVAL OF MR MED MALEKA'S STUDY TO BE CARRIED OUT IN REHABILITATION DEPARTMENTS OF THE CLINICS MENTIONED ABOVE

PURPOSE:

Rehabilitation programme has been providing rehabilitation services to people with disabilities among are the Cerebrovascular Accidents (Stroke) clients. Currently we do not have valid and reliable outcome measures to assess their level of integration into the community. Therefore the study that Mr. MED Maleka is proposing will assist the programme in developing appropriate community based rehabilitation strategies and plans.

BACKGROUND

Rehabilitation programme had a need to develop such an outcome measure. Due to lack of capacity especially therapist we could not develop the outcome measure. Then we collaborated with the above named researcher from the University of the Witwatersrand to carry out the study as part of his PhD. The above named researcher has been assisting with supervision of physiotherapy students from WITS and community service therapist based at Chiawelo and Alexander University clinic.

Hillbrow CHC – Administration Block, Corner Klein & Smith Street.
Private Bag X 21 , Johannesburg 2001.
Enq.: Tel: (011) 694-3836 Fax (011) 694-3825

As the research project meets the needs of rehabilitation programme I have no hesitation in giving Mr. MED Maleka the permission to carryout the study. May you kindly assist him and give him the necessary support.

FINANCIAL IMPLICATIONS:
None to the facility.

O.A. Memee
AD Clinical Support (REHABILITATION PROGRAMME)
JHB METRO

Hillbrow CHC – Administration Block, Corner Klein & Smith Street.
Private Bag X 21 , Johannesburg 2001.
Enq.: Tel: (011) 694-3836 Fax (011) 694-3825

APPENDIX 3.1

CHAPTER 3 APPENDICES: LETTER TO THE PROVINCES (LIMPOPO AND GAUTENG)

12/03/2008

Re: Request to carry out research in Limpopo province (Elim and Siloam Hospital)

My name is Douglas Maleka; I am a student at the University of the Witwatersrand in Johannesburg. I am currently doing my PhD. The title of my study is: **The development of an outcome measure to assess community reintegration after stroke for patients living in poor socioeconomic urban and rural communities.**

I chose Limpopo and Gauteng province as my data collection sites (see the proposal attached. In Limpopo I have chosen Elim and Siloam Hospital and clinics under these hospitals.

This letter serves to inform the department that there will be no financial implications to the hospital or province

Thank you

Regards

MED Maleka, Lecturer
Physiotherapy department, School of Therapeutics Sciences, Faculty of Health Sciences,
University of the Witwatersrand
Johannesburg
011 717 3702
082 465 4641

APPENDIX 3.2

LETTER TO PHC CLINICS MANAGEMENT

Dear Sir/Madam

Hello my name is Douglas Maleka; I am a post-graduate student registered for a PhD at the University of the Witwatersrand, in the Faculty of Health Sciences, School of Therapeutic Sciences, and Department of Physiotherapy.

The title of my study is “Development of an outcome measure to assess community reintegration following stroke **for patients living in poor socioeconomic rural and urban areas of South Africa.**

The main aim of the study is:

To develop and validate an outcome measure to assess community reintegration following stroke for patients living in poor socioeconomic rural and urban areas of South Africa.

An outcome measure is defined as a measurement tool e.g. an instrument; questionnaire or rating form used to document changes in one or more patient’s characteristics over time. By developing this outcome measure the patients with stroke will potentially be assisted by firstly assessing their level of community reintegration and assist in enhancing their level of community reintegration following stroke.

Request: May I please have access to the medical records in your clinic and patients in order for me to carry out this study. Once patients with stroke and their caregivers have been identified, then I will interview them at the clinic or their homes. Later patients will be part of a group, which will help in developing the outcome measure. There are no physical risks involved in this study and if patients do not wish to participate in the study it will not affect their management in any way as it is not an experimental study.

Your response to this matter will be highly appreciated. If permission is given will you please sign the attached consent form.

Thank you, Douglas Maleka

APPENDIX 3.3

RESPONSE FORM

The management of the clinic has read and understood the contents of the letter. We therefore give you permission to use records and patients in the study as outlined in the letter.

Signature:

Name:

Date:

APPENDIX 3.4

INFORMATION SHEET FOR PARTICIPANTS IN THE PILOT STUDY (STUDY 1)

Dear patient, Hello

Hello my name is Douglas Maleka; I am a post-graduate student registered for PhD at the University of the Witwatersrand in Johannesburg, in the Faculty of Health Sciences, School of Therapeutic Sciences-Department of Physiotherapy.

I would like to invite you to take part in the pilot study.

The title of my study is “Development of outcome measure to assess community reintegration following stroke **for patients living in poor socioeconomic rural and urban areas of South Africa.**

The main aim of the study is: To develop and validate an outcome measure to assess community reintegration following stroke for patients living in poor socioeconomic rural and urban areas of South Africa.

An outcome measure is a rating scale that will give an indication of how well you have settled in your community. The outcome measure will assist you, your family and your therapists in developing plans for your rehabilitation in the community to make you settle well into your community.

Firstly you and your family members (caregiver) will be interviewed. After the interview you will be given a chance to listen and correct your interview. The interview will be recorded on a tape and the tapes will be kept for a period of six years after the interview or two years after publication (whichever comes first) after which they will be destroyed.

The interviews are planned for 1-2 hours. You and your family members (caregiver) will be interviewed at your house or at the clinic.

If you have to travel to that clinic the researcher will cover your travelling costs.

By taking part in this study you will possibly be assisting yourself and other people who have stroke, in that the information obtained may be used to plan for the bigger study that will assist in developing an outcome measure and then assist in developing your community based rehabilitation treatments. There are no risks associated with this whole process of research.

Participation is optional, and refusal to participate will not affect your treatment at the clinic in any way. If you wish to leave before the study is complete you may do so without affecting your treatment at the clinic in any way.

What you say will be kept in secret by researchers in this interview but it cannot be guaranteed for other members of the group.

A copy of the results of the study will be made available to you if you ask for them, as soon as the write up is complete and has been approved. The tapes will be kept for two years. Your name will not be used on any of the information in this study.

If you agree to take part please will you please sign the consent form below.

Thanking you, Mr. Douglas Maleka, Physiotherapist

APPENDIX 3.5

CONSENT FORM FOR PILOT STUDY PARTICIPANTS AND FOR AUDIO TAPING THE INTERVIEW

I have read and understood the contents of the information sheet. I therefore consent to participate in the pilot study as outlined in the information sheet.

Patient and caregiver's names:

Signature

Date:

APPENDIX 3.6

PATIENT AND CAREGIVER INFORMATION SHEET (STUDY 1)

Dear patient, Hello

Hello my name is Douglas Maleka; I am a post-graduate student registered for PhD at the University of the Witwatersrand in Johannesburg, in the Faculty of Health Sciences, School of Therapeutic Sciences-Department of Physiotherapy.

I would like to invite you to take part in a study that I am about to start.

The title of my study is "Development of an outcome measure to assess community reintegration following stroke **for patients living in poor socioeconomic rural and urban areas of South Africa.**

The main aim of the study is:

To develop and validate an outcome measure to assess community reintegration following stroke for patients living in poor socioeconomic rural and urban areas of South Africa.

An outcome is a rating scale that will give an indication of how well you have settled in your community. The outcome measure will assist you, your family and your therapists in developing plans for your rehabilitation in the community to make you settle well into your community.

Firstly you and your family members (caregiver) will be interviewed. After the interview you will be given a chance to listen and correct your interview. The interview will be recorded on a tape and the tapes will be kept for a period of six years after interviews or two years after publication (which ever comes first) after which they will be destroyed.

The interviews are planned for 1-2 hours. You and your family members (caregiver) will be interviewed at your house or at the clinic and about your condition.

Secondly you will be invited to meetings where the information gained from the interview will be used to develop the outcome measure. There are 2-3 of meetings planned before we finalise it. The meetings will be run for 1-2 hours per meeting. The meetings will be taking place in a clinic where most of the patients are coming from. If you have to travel to that clinic the researcher will cover your travelling costs.

By taking part in this study you will possibly be assisting yourself and other people who have stroke, in that the information obtained may be used to plan for community-based rehabilitation treatment. There are no risks associated with this whole process of research.

Taking part is optional, and refusal to participate will not affect your management at the clinic in any way. If you wish to leave the study at any time you may do so, also without affecting any treatment that you get at the clinic.

What you say will be kept in secret by researchers in this interview but whether other members of the group will do the same I cannot be certain. Your name will not be used on any of the information used in this study.

A copy of the results of the study will be made available to your on request, as soon as the write up is complete and has been approved.

If you agree to take part in the study will you please sign a consent form below.

Thanking you, Mr. Douglas Maleka, Physiotherapist

APPENDIX 3.7

CONSENT FORM TO AUDIOTAPE THE INTERVIEW FOR PATIENTS AND CAREGIVERS

I have read and understood the contents of the information sheet. I therefore consent to participate and for the interview to be audio taped as outlined in the information sheet.

Patient and caregivers name:

Signature:

Date:

APPENDIX 3.8

CONSENT FORM FOR PATIENTS AND CAREGIVERS TO PARTICIPATE IN THE STUDY (INTERVIEW)

I have read and understood the contents of the information sheet. I therefore consent to participate in the study as outlined in the information sheet.

Patient and caregivers name:

Signature:

Date:

APPENDIX 3.9

PILOT STUDY, THE INITIAL INTERVIEW PROMPTS/GUIDE

Introduction:
Researcher: My name is Douglas Maleka, I am doing a study to find out how you are living now after the stroke so that I can assist in developing a tool/scale that will check how well you and other patients with stroke have settled into their community following your stroke and I have a consent form that I need you to sign for me before we start with the interview if you agree to be interviewed.

Reading and explanation of the information sheet and signing of consent forms. (This will be done in the language that the patient is comfortable with)

Researcher: Before we start with the interview I would like to inform you that this interview will be taped and that I need to take some of your information e.g. how old are you etc. on a separate piece of paper.

Capturing of demographic data.
1. Tell us about your family
2. When did you have a stroke?
3. What caused your stroke?
4. What corrective measure(s) did you take? What did you do to correct your stroke?
5. What do you understand stroke to be? Or what is stroke?
6. How long have you been staying in this community before and following stroke?
7. Can you please describe a typical day? How do you fill/spend your day?
8. Has your life changed following stroke? Please explain the changes to me.
9. Do you think that you have settled back into your community well following the stroke? Please explain your answer
10. Can you please explain how the changes you have experienced as a result of the stroke have affected your settling in the community following a stroke?
Thank you

APPENDIX 3.10

AN EXAMPLE OF THE INITIAL INTERVIEW PROMPT/GUIDE TRANSLATED TO ISIZULU

Sawubona, Igama la mi ngu Douglas Maleka. Ngizo cela ukubuza imiboza mailana ne stroke sa kho. Ngi funa ugwazi uguthi solokhu wa shawa hi stroke impilo ya kho injana na. Leyo mibuzo izonginceda ukuthi ngikwazi ukuthi si-checke abantu bestroke, abashaywe i-stroke ukuthi kuhambe kanjani ngabo seloku bashaywe i-stroke. U ma uvuma ngi cela u ngi signele le.

Imibozo nge mpilo ya kho

1. Ngi cela ungi tshele ngo mdeni wa kho.
2. Si gu shaye nini istroke?
3. Istroke sa kho sabangwe hini?
4. U yenze njani ugu lungisa istroke sa kho?
5. i-stroke yini na?
6. Uqale ukuhlala nini la eChiawelo?
7. Ngicela nje ukuthi ilanga lakhe ulidla njani? Ukuthi wenzani ekuseni, emini nasentambama.
8. Solokhu washaywa istroke, impilo yakho ishintshile na? Ngi cela u caze
9. Solokhu washaywa istroke, sewukwazile ukuthi ungabuyela uhlale emphakathini wakho njengoba bewuhleli ushaywe istroke?
10. Manje ukuze uthi wena ubuyele uhlala futhi uphila impilo le oboyiphila before ushaywa istroke, yini le engakwenza ukuthi usho ukuthi manje sengibuyele, ngiphila leyo mpilo leyo ebengiyiphila before ngishaywe istroke?

    Ngiyabonga

APPENDIX 3.11

ADAPTED INTERVIEW PROMPT/GUIDE

Introduction:
Researcher: My name is Douglas Maleka, I am doing a study to find out how you are living now after the stroke so that I can assist in developing a tool/scale that will check how well you and other patients with stroke have settled into their community following your stroke and I have a consent form that I need you to sign for me before we start with the interview if you agree to be interviewed.

Reading and explanation of the information sheet and signing of consent forms. (This will be done in the language that the patient is comfortable with)

Researcher: Before we start with the interview I would like to inform you that this interview will be taped and that I need to take some of your information e.g. how old are you etc. on a separate piece of paper.

Capturing of demographic data.

1. Tell us about your family
2. Can you please describe a typical day? How do you fill your day?
3. Has your life changed following the stroke? Please explain the changes to me.
4. Do you think that you have settled back into your community well following the stroke? Please explain your answer
5. What activities or things would indicate that you have settled back well into your community following the stroke?

APPENDIX 3.12

AN EXAMPLE OF THE ADAPTED INTERVIEW PROMPT/GUIDE TRANSLATED TO TSHIVENDA

Mathomele:

Musedzulusi: Dzina langa ndi Douglas Maleka, ndi ita ngudo dza tsedzuluso ya matshilele avho a zwino u tevhela u oma lurumbu uri zwi kone u nthusa kha uvha na tshikeili kana tshekalo tsha u sedzulusa uri motakalo wavho u hana na vhanwe vhare na u oma lurumbu vho dzulusea hani tshitshavhane vhani utevhela u oma lurumbu lwavho na uri ndi ndina fomo ya thendelo ine nda toda vhone vha tshi I saina musi risa athu uthoma nga ha tsedzuloso a rali vha tshi khuo ntendela.

Musedzulosi: musi ri sa uthu uthoma ndi tama u vha dzivhadza uri heyi tshedzuloso I dovha I tshi khou rikhodiwa uri rikone u wana inwe ndivho khavho tsumbo vhana minwhaha mingani kha zwi mambiri

1. Musedzulosi: Re hombela ure kha vha re dibadze muta wa vho.
Mulwadzi/Muthogomeli a tshi fhindula
2. Musedzulosi: Kha vha talutshedze zwine vha zwi ita duvha na duvha.
Mulwadzi/Muthogomeli a tshi fhindula
3. Musedzulosi: Vha nga ntalutshedza uri vhutshilo havho ho shandunkisa hani nga murahu ha musi vho u oma lurumbu?
Mulwadzi/Muthogomeli a tshi fhindula
4. Musedzulosi: vha humbula uri vha nga kha di kona u ita zwe vha vha vha tshi zwi ita vha sa a thu u oma lurumbu?
Mulwadzi/Muthogomeli a tshi fhindula
5. Musedzulosi: Vha nga talutshedza uri vho kwamea zwingafhani nga murahu ha u oma lurumbu
Mulwadzi/Muthogomeli a tshi fhindula

Lwa u fhedzisela ndi tama u livhuwa mulwadze na muthogomeli. Mulwadze na muthogomeli vha do divhadziwa nga ha datumu ya mutangano wa u thoma na vha koni na vha mbalavhathu

Ndi zwone

APPENDIX 3.13

ITEMS GENERATED

1. ACTIVITIES OF DAILY (14 items)

Since your stroke:

1.1 Are you able to get up in the morning?

1.2 Are you able to pour water into a kettle?

1.3 Are you able to pour water into the basin?

1.4 Are you able to wash yourself fully?

1.5 Are you able to dress yourself fully?

1.6 Are you able to feed and drink from a cup?

1.7 Are you able to take a walk in your home, yard or community?

1.8 Are you able to do exercises you were shown by the therapist at the hospital or clinic?

1.9 Are you able to speak (converse) with your family members or people in your area?

1.10 Are you able to easily remember things told, events?

1.11 Are you able to use your hand for example to write or to hold a cup of tea

1.12 Are you able to walk in confined spaces and uneven areas?

1.13 Are you able to carry a heavy object for example shopping bags?

1.14 Are you able to go to the hair salon or barber shop?

2. HOME RESPONSIBILITY (14 items)

2.1 Are you able to clean your house?

2.2 Are you able to wash and dry dishes?

2.3 Are you able to cook on the stove/ground fire?

2.4 Are you able to wash, hang and iron your clothes?

2.5 Are you able to sew or knit?

2.6 Are you able to work in your garden or fields i.e. plough, plant flowers, mow the lawn, cut trees, take the weed out?

2.7 Are you able to fix a hole in your fence?

2.8 Are you able to take care of your animals e.g. feed your dogs or walk them or shepherd your cattle/goats?

2.9 Are you able to clean your yard i.e. pick up papers, decorate your yard?

2.10 Are you able to collect firewood, chop and prepare fire?

2.11 Are you able to mud your floor with cow dung or soil?

2.12 Are you able to collect water from the river/communal tap?

2.13 Are you able to grind the mealie meal?

2.14 Are you able to teach your children/grandchildren culturally appropriate home tasks like mudding with cow dung?

3. FAMILY RESPONSIBILITY (4 items)

3.1 Are you able to take care of your children or grandchildren with their basic needs e.g. bath them, take them on a walk, collect from school, and prepare a sandwich for them?

3.2 Are you able to build your house?

3.3 Are you able to cook and prepare meals for your family?

3.4 Are you able to milk cows?

4. COMMUNITY RESPONSIBILITY (11 items)

4.1 Are you able to attend funerals, parties or weddings in your community?

4.2 Are you able to accompany your children, family members or people when they have visited you?

4.3 Are you able to attend burial society or social club meetings in your community?

4.4 Are you able to carry out your community leadership roles?

4.5 Are you able to assist with the digging of a grave in your community?

4.6 Are you able to attend “Khoro” meetings as called by the chief/Induna of your village?

4.7 Are you able to attend other structures meeting e.g? Community policing forum and school governing body

4.9 Are you able to take part in your community development projects?

4.10 Are you able to take care of elderly people in your community?

5. RELIGION (5 items)

5.1 Are you able to attend church or home cell meetings or other church activities?

5.2 Are able to preach or evangelize to people?

5.3 Are you able to bury your congregants?

5.4 Are you able to attend the Thursday or Wednesday women’s meetings at church?

5.5 Are you able to sing in the church choir?

6. EDUCATION (1 item)

6.1 Are you able to attend school or training programmes in your community?

7. RELATIONSHIPS (4 items)

7.1 Are you able to relate to your spouse/partner sexually?

7.2 Are you able to relate to people of the opposite sex/same sex?

7.3 Are you able to interact with other people?

7.4 Are you able to physically assist other people?

8. MEDICAL CARE (2 items)

8.1 Are you able to collect your medication from the nearest clinic or hospital?

8.2 Are you able to take your medication?

9. RECREATION (8 items)

9.1 Are you able to listen to a radio?

9.2 Are you able to watch TV?

9.3 Are you able to go shopping in town?

9.4 Are you able to read a book or a bible?

9.5 Are you able to play sport e.g. soccer/netball or coach young boys or girls in your community?

9.6 Are you able to hunt?

9.7 Are you able to help train others in activities such as cultural, traditions, cooking, acting, coach a sport?

9.8 Are you able to get out of the house to e.g. night disco clubs?

10. PRODUCTIVITY (2 item)

10.1 Are you working or intending to return to work?

10.2 Are you able to volunteer work?

11. TRAVEL AND TRANSPORT (2 items)

11.1 Are you able to drive?

11.2 Are you able to get into a taxi or car or bus or train?

APPENDIX 3.14

THE DEMOGRAPHIC CHARACTERISTICS OF THE PARTICIPANTS

Age:

Physical address of the patient:

Gender:

Race:

Years of formal education:

Current employment status:

Occupation (previous or current):

Marital status:

Caregiver (formal or informal):

Date of the stroke:

Side of hemiplegia:

Name of the interviewer:

Date of the interview:

Location where the interview was conducted:

Who was interviewed: patient or caregiver?

APPENDIX 4.1A

CHAPTER 4 APPENDICES: INFORMATION SHEET FOR PATIENTS PARTICIPATING IN NOMINAL GROUP TECHNIQUE-STUDY 2, PHASE 1

Re: An invitation to participate in group meeting to check a newly developed outcome measure of community reintegration following stroke.

Dear participant

I am a post-graduate student registered for a PhD degree at the University of the Witwatersrand, in the Faculty of Health Sciences, School of Therapeutic Sciences, Physiotherapy Department.

The title of my thesis is "**Development of an outcome measure to assess community reintegration following stroke for patients living in poor socioeconomic rural and urban areas of South Africa** and I would like to invite you to participate in a Delphi expert panel to validate this outcome measure.

The main aim of the study **is to develop and validate an interviewer administered outcome measure to assess community reintegration following a stroke.** This outcome measure will potentially be beneficial for patients with stroke like you, as it will assess their present level of community reintegration and guide intervention to enhance level of community reintegration following stroke.

In the first step to develop this OM I interviewed patients with stroke and their caregivers in order to define community reintegration from their perspective. From the results of the first step I developed an OM. I would like to check this newly developed OM with patients with stroke, such as yourself. I would therefore like to invite you to be part of these meetings.

The meeting will involve you commenting and agreeing on which questions to keep or exclude, in the OM. I will therefore invite you to comment, whether the question read to you is:

- clear and understandable?
- important for your community reintegration following?
- culturally/context appropriate?

I will collate all the responses received per meeting and send these responses out to the expert group for more input until an agreement is reached.

Your input into these meetings will greatly assist in further developing the outcome measure. The information from these meetings will be kept confidential by the researcher and members of the group will be asked to keep any received information confidential, however I cannot guarantee that all the members will keep the information confidential. Taking part in this part of the study is completely voluntary.

If you accept the invitation, please sign the consent form below and return it to me after the meeting. You will be kept informed of the developments of this study.

Thanking you in anticipation

Yours sincerely

Mr. Morake Douglas MALEKA
Lecturer/ PhD candidate
Physiotherapy Department
School of Therapeutic Sciences, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg

APPENDIX 4.1B

CONSENT FORM FOR PATIENTS TO PARTICIPATE IN THE STUDY (NOMINAL GROUP TECHNIQUE)-STUDY 2, PHASE 1

I have read and understood the contents of the information sheet. I therefore consent to participate in the study as outlined in the information sheet.

Setting: Urban or rural
Age:
Gender:
Marital status:
Access to caregiver:
Level of formal education obtained:
Side of hemiplegia:
Date of Stroke:
Employment status:
Location of the interview:
Signature:
Date:

APPENDIX 4.2A

INFORMATION FOR EXPERTS PARTICIPATING IN THE DELPHI TECHNIQUE-STUDY 2, PHASE 1

Re: An invitation to participate in an expert panel to validate a newly developed outcome measure of community reintegration following stroke.

Dear colleagues

I am a post-graduate student registered for a PhD degree at the University of the Witwatersrand, in the Faculty of Health Sciences, School of Therapeutic Sciences, Physiotherapy Department.

The title of my thesis is "**Development of an outcome measure to assess community reintegration following stroke for patients living in poor socioeconomic rural and urban areas of South Africa** and I would like to invite you to participate in a Delphi expert panel to validate this outcome measure.

The main aim of the study **is to develop and validate an interviewer administered outcome measure to assess community reintegration following stroke.** This outcome measure will potentially be beneficial for patients with stroke as it will assess their present level of community reintegration and guide intervention to enhance level of community reintegration following stroke.

In the first step to develop this OM I interviewed patients with stroke and their caregivers in order to define community reintegration from their perspective. From the results of the first step I developed a preliminary OM. I would like to validate this preliminary OM with rehabilitation experts, such as yourself. I would therefore like to invite you to be part of this expert panel. You have been selected based on your experience with rehabilitation of patient with stroke in a community setting and knowledge about community based interventions.

The Delphi technique involves sequential rounds of comments from expert panel members until consensus is reached. I will therefore invite you to comment,

- firstly on the number of items and appropriateness in the OM (first round),
- secondly the scoring system of the OM (second round)
- and lastly and finally whether you think the items included in the OM are indeed measuring community reintegration in the context of our country (third round).

I will collate all the responses received per round and send these responses out to all in the expert group for more input until an agreement is reached that all questions in the OM are valid for the purpose of measuring community reintegration following stroke in the South African context.

Your input into this Delphi technique will greatly assist in further developing the outcome measure. The information from the Delphi will be kept confidential by the researcher and members of the expert panel will be asked to keep any received information confidential, however I cannot guarantee that all the members will keep the information confidential. Taking part in this part of the study is completely voluntary.

If you accept the invitation, please sign the consent form below and return it to me via fax (011 717 3719). You will be kept informed of the developments of this study.

Thanking you in anticipation

Yours sincerely

Mr. Morake Douglas MALEKA
Lecturer/ PhD candidate
Physiotherapy Department
School of Therapeutic Sciences, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg

APPENDIX 4.2B

CONSENT FORM FOR EXPERTS TO PARTICIPATE IN THE DELPHI TECHNIQUE STUDY 2, PHASE ONE

I have read and understood the contents of the information sheet. I therefore consent to participate in the study as outlined in the information sheet.

Profession:
Qualification(s):
Years of practicing as a community based therapist and/or neurological rehabilitation therapist:
Province where you are practicing:
Date:
Signature:

APPENDIX 4.3

THE DELPHI ROUND 1: THE DEFINITION AND COMPONENTS OF COMMUNITY REINTEGRATION FROM THE LITERATURE

Various studies have been conducted with the hope of identifying and defining the components of community reintegration. The studies below generally highlight some of the components of community reintegration. Wood-Dauphinee et al, (1988) defined "integration as the organization of organic, psychological, and social traits and tendencies of an individual into a harmonious whole. Therefore reintegration to normal living could mean the reorganization of physical, psychological and social characteristics so that the individual can resume well-adjusted living after an incapacitating illness or trauma like stroke" (Wood-Dauphinee et al 1988).

The definition came about when the researchers were developing the Reintegration to Normal Living Index. The purpose of the index is to assess the global functional status of patients who require long-term rehabilitation. The information to determine the components of the index was collected through interviews with professionals, patients and caregivers. The results suggested that the following domains are related to reintegration to normal living, namely

- indoor activities,
- community and distant mobility,
- self-care and daily activity,
- recreational and social activities,
- general coping skills,
- family roles,
- personal relationships
- and presentation of self to others (Wood-Dauphnee et al, 1988).

McGrew et al, (1992) identified the seven factors constituting community reintegration to be

- occupation,
- residential environment,
- social support,
- overall satisfaction,
- leisure participation,
- family contact and
- community assimilation and
- acceptance (self and community).

Willer et al, (1994) in their Community Integration Questionnaire identified three factors constituting community integration:

- To be home, this refers to the person's ability to do household chores and care for self and children.
- Social, referring to the ability to be able to do shopping, visit relatives, friends and undertake leisure activities, and
- Productivity, which refers to the ability of a person to work and do voluntary jobs.

The term community reintegration according to Dijkers et al, (1998) is used in the human services field like health and correctional services to refer to being part of the mainstream of family and community life, discharging normal roles and responsibilities, and being an active and contributing member of one's social group and of society as a whole. Dijkers et al, (1998) in his Community Integration Framework included the following attributes of community reintegration:

- activities of daily living,
- independent living,
- social health,
- social adjustment
- and quality of life.

Trigg and Wood (2000), in their Subjective Index of Physical and Social Outcome (SIPSO) identified four components of community reintegration namely:

- Activities (In home and outside home)
- Leisure
- Interaction which refers to relationships
- Environment: physical-home and community and financial

McColl et al, (2001) in their Community Integration Measure identified four factors constituting community reintegration to be:

- assimilation referring to conformity,
- orientation and acceptance,
- social support refers to both close and diffuse relationships;
- occupation in this instance refers to leisure and productivity and finally
- Independent living refers to personal independence, satisfaction with living arrangement.

Van Brackel et al, (2006) in their Participation Scale (ICF 2001) included the following attributes as part of community integration:

- Relationships,
- Community life,
- Recreation and leisure,
- Education,
- Work,
- Economic and assisting others.

As can be seen in the studies above, the definition and the components of community reintegration are contextual; however there are some similarities and differences in the definitions and components of community reintegration.

APPENDIX 4.4

THE DELPHI ROUND 1 RESPONSE FORM (60 ITEMS)

1. ACTIVITIES OF DAILY AND PERSONAL CARE (15 items)

Since your stroke:

Item	Must Include	Possibly Include	Exclude
1.1 Are you able to get up and out of bed in the morning?			
1.2 Are you able to pour water into a kettle?			
1.3 Are you able to pour water into the basin?			
1.4 Are you able to wash yourself?			
1.5 Are you able to dress yourself?			
1.6 Are you able to feed yourself?			
1.7 Are you able to drink from a cup or glass?			
1.8 Are you able to use your hand to write?			
1.9 Are you able to carry a heavy object for example shopping bags?			
1.10 Are you able to walk in confined spaces and uneven/hilly areas?			
1.11 Are you able to take a walk in your home, yard or community?			
1.12 Are you able to go to the hair salon or barber shop for grooming yourself?			
1.13 Are you able to do the exercises you were shown by your therapist at home?			
1.14 Are you able to converse with your family members or people in your area?			
1.15 Are you able to easily remember things told and events?			

2. **HOME AND FAMILY RESPONSIBILITIES (18 items)**

Since your stroke:

Item	Must Include	Possibly Include	Exclude
2.1 Are you able to clean your house?			
2.2 Are you able to clean your yard i.e. pick up papers, decorate your yard?			
2.3 Are you able to work in your garden or fields e.g. plough, plant flowers, mow the lawn, cut trees, and take the weed out?			
2.4 Are you able to cook and prepare meals for your family?			
2.5 Are you able to cook on the stove/ground fire?			
2.6 Are you able to wash the dishes?			
2.7 Are you able to wash the clothes?			
2.8 Are you able to hang the clothes on a washing line?			
2.9 Are you able to iron the clothes?			
2.10 Are you able to sew or knit?			
2.11 Are you able to take care of your livestock e.g. feed your dogs or walk them or shepherd your cattle/ goats?			
2.12 Are you able to milk cows?			
2.13 Are you able to collect firewood, chop and prepare fire?			
2.14 Are you able to mud your floor with cow dung or soil?			
2.15 Are you able to collect water from the river/communal tap?			
2.16 Are you able to grind the mealies?			
2.17 Are you able to teach your children/grandchildren culturally appropriate home tasks like mudding with cow dung?			
2.18 Are you able to take care of your children or grandchildren with regards to their basic needs e.g. bath them, drop and collect from school?			

3. **COMMUNITY AND SOCIAL RESPONSIBILITIES (6 items)**

Since your stroke:

Item	Must Include	Possibly Include	Exclude
3.1 Are you able to attend social events in your community such as funerals, parties or weddings?			
3.2 Are you able to attend burial society or social club meetings in your community?			
3.3 Are you able to carry out your community leadership roles e.g. preaching or evangelizing to people or burying your congregants?			
3.4 Are you able to assist with the digging of a grave in your community?			
3.5 Are you able to attend meetings as called by the chief/Induna or councilor of your village/area?			
3.6 Are you able to attend other structures meeting e.g. community policing forum and school governing body?			

4. **RELIGION (2 items)**

Since your stroke:

Item	Must Include	Possibly Include	Exclude
4.1 Are you able to attend church/religious/spiritual and other church related activities e.g. bible studies, home cell meetings?			
4.2 Are you able to attend the Thursday or Wednesday prayer meetings at church?			

5. **EDUCATION (2item)**

Since your stroke:

Item	Must Include	Possibly Include	Exclude
5.1 Are you able to attend school or training programmes in or out of your community? “Adult education included”			
5.2 Are you able to help train others in activities such as cultural/traditional cooking, acting, or coaching a sport?			

6. **RELATIONSHIPS (4 items)**

Since your stroke:

Item	Must Include	Possibly Include	Exclude
6.1 Are you able to be intimate with your spouse/partner?			
6.2 Are you able to interact and relate generally to people of the opposite sex/same sex?			
6.3 Are you able to physically assist other people?			
6.4 Are you worried about your appearance when out in public?			

7. **TRAVEL/ TRANSPORT (4 items)**

Since your stroke:

Item	Must Include	Possibly Include	Exclude
7.1 Are you able to collect your medication from the nearest clinic or hospital?			
7.2 Are you able to drive?			
7.3 Are you able to get into a taxi or car or bus or train or donkey cart?			
7.4 Are you able to get to the clinic/hospital for rehabilitation?			

8. **RECREATION AND LEISURE (6 items)**

Since your stroke:

Item	Must Include	Possibly Include	Exclude
8.1 Are you able to listen to a radio?			
8.2 Are you able to watch TV?			
8.3 Are you able to read a book or a bible?			
8.4 Are you able to play sport e.g. soccer/netball in your community?			
8.5 Are you able to help train others in activities such as cultural/ traditions cooking and dancing, acting, coaching a sport?			
8.6 Are you able to get out of the house to go shopping in town, going out with friends to watch a movie, go to a night club, watch a soccer match at a stadium?			

9. **PRODUCTIVITY (3 item)**

Since your stroke:

Item	Must Include	Possibly Include	Exclude
9.1 Are you working or intending to return to work?			
9.2 Are you able to do volunteer work in your community?			
9.3 Are you able to take part in your community development projects?			

APPENDIX 4.5

THE DELPHI TECHNIQUE ROUND 1 RESULTS

1. ACTIVITIES OF DAILY LIVING AND PERSONAL CARE (8/18 items)

Table 4.3: Items No Consensus Reached

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
1.2 Are you able to pour water into a kettle/basin?	2/10	20%	None
1.3 Are you able to pour water into the basin?	3/10	30%	Included in 1.2.
1.8 Are you able to write or draw a cross?	4/10	40%	Need to take into account the people who can't write.
1.12 Are you able to go to the market/shop/hair salon or barber shop?	5/10	50%	Exclude, if patients are able to move around they can go anywhere including market.
1.13 Are you able to do the home exercises you were shown by your therapist?	3/10	30%	Not sure if this measure community reintegration?
1.17 Are hopeful that you will get better? b) Are you not hopeful that you will ever get better?	3/10	30%	Is this really a measure of community reintegration or emotional state?

Table 4.4: Item to be Added to Domain 1

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
1.18 Are you able to get to the toilet and use it independently?			New question, to be sent out in the second round. Though part of it is covered in 1.11, if they patient can move around their home then they should be able to go to the toilet.

Table 4.6: Items No Consensus Reached

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
2.2 Are you able to clean your yard i.e. sweep, pick up papers?	4/10	40%	Could be implied in 2.1, therefore combine the two.
2.3 Are you able to work in your garden or fields? a) plough, b) Plant flowers, c) Mow the lawn, d) Cut trees e) and take the weed out?	6/10	60%	Separate the tasks; mowing the lawn is not as applicable for rural setting or just state as an example.
2.5 Are you able to cook on the stove/ground fire?	4/10	40%	Exclude, not appropriate for all, combine with 2.4. If they can prepare food does it matter where they prepared it stove/open fire?
2.8 Are you able to hang the clothes on a washing line?	7/10	70%	None
2.9 Are you able to iron the clothes?	5/10	50%	None
2.10 Are you able to sew or knit?	2/10	20%	Gender specific.
2.11 Are you able to take care of your livestock e.g. feed your dogs or shepherd your cattle/ goats, goat/cow milk?	4/10	40%	Not applicable for all patients especially urban communities. Combine with 2.12.
2.12 Are you able to milk cows?	3/10	30%	Exclude or include in the above item and only if it was the patient's main role. It is implied in 2.11.
2.13 Are you able to collect firewood, chop and prepare fire?	5/10	50%	Exclude or include in the above item and only if was the patient's main role.
2.14 Are you able to mud your floor with cow dung or soil?	4/10	40%	Exclude or include in the above item and only if it was the patient's main role, not applicable to all settings.
2.16 Are you able to grind the mealies?	5/10	50%	Exclude or include in the above item and only if it was the patient's main role, not applicable to all settings anymore?
2.17 Are you able to teach children home keeping tasks e.g.? Mudding with cow dung, ploughing?	5/10	50%	Change it so that it is more generic like: "Are you able to teach children home keeping tasks e.g.? Give more generic example so that it's not so culture specific.
2.18 Are you able to take care of your children or grandchildren with regards to their basic needs? a)bath b) drop and c) Collect from school?	6/10	60%	Divide into two questions or put differently it is too long.

3. **COMMUNITY AND SOCIAL RESPONSIBILITIES (2/6 items)**

Table 4.8: Items No Consensus Reached

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
3.3 Are you able to carry out your community leadership and other community roles e.g. preaching or evangelizing to people or burying your congregates, digging of a grave, singing in the choir, helping at the local school?	4/10	40%	Only applicable if one was a leader. Could also be in the religion domain 4.
3.4 Are you able to assist with the digging of a grave in your community?	2/10	20%	Exclude as it is included in 3.3, some villages there are volunteers who dig graves.
3.5 Are you able to attend meetings as called by the chief/Induna or councilor of your village/area?	6/10	60%	Exclude or Combine with 3.5 and or 3.2.
3.6 Are you able to attend other community structures meeting e.g. community policing forum and school governing body?	5/10	50%	Exclude or Combine with 3.4 and/or 3.2.

4. **RELIGION (1/2 items)**

Table 4.10: Items No Consensus Reached

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
4.2 Are you able to attend the Thursday or Wednesday prayer meetings at church?	3/10	30%	Could be one of the examples in 4.1. Could include in 4.1 sound similar.

5. **RELATIONSHIPS (4/8 items)**

Table 4.12: Items No Consensus Reached

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
5.3 Are you able to physically assist other people?	4/10	40%	Could be excluded affects flow and too general.

Table 4.13: Item to be Added to Domain 5

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
5.5 Are you able to accept help and support, including emotional support from family and friends?			New item suggested, being included in the second round.
5.7 Are you able to solve problems with family and friends			New item suggested, being included in the second round.
5.8 Do you have friends and family who visit you at home?			New item suggested, being included in the second round.

6. **TRAVEL/ TRANSPORT (3/5 items)**

Table 4.15: Items No Consensus Reached

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
6.2 Are you able to drive?	3/10	30%	Combine with 7.3. Only applicable if able to drive before.

Table 4.16: Item to be Added to Domain 6

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
6.5 Are your friends and family assisting you with your travelling needs?			New item suggested, to be included in the second round.

7. **RECREATION AND LEISURE (1/4 items)**

Table 4.18: Items No Consensus Reached

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
7.1 Are you able to listen to a radio?	6/10	60%	Combine and put as an example to a question "Are you able to do an activity for self enjoyment or relaxation?"
7.1 Are you able to watch TV?	7/10	70%	None
7.1 Are you able to read a book/ bible/newspaper/magazine?	7/10	70%	None
7.2 Are you able to do a physical activity such as playing any sport?"	6/10	60%	Repetitive, exclude this item. Only if did sports before stroke. I Suggest to rephrase to a more generic item like "Are you able to do a physical activity such as playing any sport?"
7.3 Are you able to help train others in activities such as cultural/ traditions cooking and dancing, acting, coaching a sport?	2/10	20%	Repetitive, exclude this item. Only applicable if used to doing this before stroke.

8. **PRODUCTIVITY (1/3 item)**

Table 4.20: Items No Consensus Reached

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
8.2 Do you do volunteer work?	6/10	60%	Similar to 9.3, use only one. Only if did before stroke, may not be applicable to all.
8.3 Are you able to take part in your community development projects?	3/10	30%	Covered already in other domains/items.

9. **EDUCATION (0/2 items)**

Table 4.21: Items No Consensus Reached

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
8.4 Are you able to attend school or training programmes in or out of your community? "Adult education included"	7/10	70%	As a participant or trainer? Does it matter? Applicable if the person was doing this before stroke.
8.5 Are you able to help train others in activities at home such as a) cultural/traditional cooking, and in the community such as	2/10	20%	Exclude not common to most patients.
b) Acting, or coaching a sport?			

APPENDIX 4.6

THE DELPHI ROUND 2 RESPONSE FORM (28 ITEMS)

1. **ACTIVITIES OF DAILY LIVING AND PERSONAL CARE (6 items):**

Since your stroke:

Item	Include	Exclude	Comments
1.2 Are you able to pour water into a kettle/basin?			
1.8 Are you able to write or draw a cross?			
1.12 Are you able to go to the market/shop/ hair salon or barber shop?			
1.13 Are you able to do the home exercises you were shown by your therapist?			
1.17a) Are hopeful that you will get better?			
b) Are you not hopeful that you will ever get better?			

2. **HOME AND FAMILY RESPONSIBILITIES (11 items):**

Since your stroke:

Item	Include	Exclude	Comments
2.2 Are you able to clean your yard i.e. sweep, pick up papers?			
2.3 Are you able to work in your garden or fields?			
2.8 Are you able to hang the clothes on a washing line?			
2.9 Are you able to iron the clothes?			
2.10 Are you able to sew or knit?			
2.11 Are you able to take care of your livestock e.g. feed your dogs or shepherd your cattle/ goats, including milking?			
2.13 Are you able to collect firewood, chop and prepare fire?			
2.14 Are you able to mud your floor with cow dung or soil?			
2.16 Are you able to grind the mealies?			
2.17 Are you able to teach children home keeping tasks e.g. cultural/traditional cooking, and mudding with cow dung?			
2.18 Are you able to take care of your children or grandchildren with regards to their basic needs e.g.?			
a) Bath			
b) Drop and Collect from school?			

3. **COMMUNITY AND SOCIAL RESPONSIBILITIES (1 item)**

Since your stroke:

Item	Include	Exclude	Comments
3.3 Are you able to carry out your community leadership and other community roles e.g. preaching or evangelizing to people or burying your congregants, digging of a grave, singing in the choir, helping at the local school?			

5. **RELATIONSHIPS (4 items)**

Since your stroke:

Item	Include	Exclude	Comments
5.3 Are you able to physically assist other people?			
5.5 Are you able to accept help and support, including emotional support from family and friends?			
5.7 Are you able to solve problems with family and friends?			
5.8 Do you have friends and family who visit you at home?			

6. **TRAVEL/TRANSPORT (2 items)**

Since your stroke:

Item	Include	Exclude	Comments
6.2 Are you able to drive?			
6.5 Are your friends and family assisting you with your travelling needs?			

7. **RECREATION AND LEISURE (2 items):**

Since your stroke:

Item	Include	Exclude	Comments
7.1 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?			
7.4 Are you able to do a physical activity such as playing any sport?			

8. **WORK AND EDUCATION (2 items):**

Since your stroke:

Item	Include	Exclude	Comments
8.2 Do you do volunteer work?			
8.1 Are you able to attend school or training programmes in or out of your community? “Adult education included”			

APPENDIX 4.7

THE DELPHI TECHNIQUE ROUND 2 RESULTS

1. ACTIVITIES OF DAILY LIVING AND PERSONAL CARE:

Table 4.23: Items to Exclude

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
1.12 Are you able to go to the market/shop/ hair salon or barber shop?	7/10	70%	Covered in 1.11. If they can go anywhere in the community, why specify this places?
1.13 Are you able to do the home exercises you were shown by your therapist?	6/10	60%	Not sure if this is participation. Very important especially that the evidence is pointing towards home and community programs. I am concerned that too few will have been exposed to a therapist, many reasons for this.
b) Are you not hopeful that you will ever get better?	2/10	20%	Opposite of 1.17, thus not necessary to include, your previous question (1.17a) gets the same information and is much clearer. Is this measuring community participation or depression/emotional related question?

2. **HOME AND FAMILY RESPONSIBILITIES**

Table 4.25: Items Excluded

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
2.9 Are you able to iron the clothes.	6/10	60%	Ask if they have an iron. Combine with 2.9, Most men not expected to this task, therefore too gender specific.
2.10 Are you able to sew or knit?	5/10	50%	Relevant for females, you will need to allow participants to tick N/A. Too sexiest, most men would not do this task- this item has potential to skew the results.
2.14 Are you able to mud your floor with cow dung or soil?	6/10	60%	Interesting, obviously this is still common practice from your findings. I still think exclude it is part of a cleaning activity and is covered in 2.1 and you could add it there. First find out what kind of floors they have and how they used to care for it. In townships people wouldn't have a mud floors. Rather use an additional example to accommodate the urban patients as well.
2.16 Are you able to grind the mealies?	6/10	60%	Ask if they did this task before stoke. Is this using the machine or is there another method they use. Not relevant in many rural households anymore. Many grow mealies and then don't stamp the mealies themselves anymore; they take them to the closest roller mill, which then grind their mealies for them for some payment, therefore exclude.
2.18 Are you able to take care of your children or grandchildren with regards to their basic needs? e.g.? a) Bath	7/10	70%	Leave out the options a) and b) otherwise it is going to be too long. Many rural children walk to school with the bigger children and parents don't drop/collect them. Sounds disjointed now with aspects unrelated to a large number of people.
b) Drop and Collect from school?			See comments above.

Table 4.31: Item to be Excluded

Item	Number of response (n)	Level of consensus/ agreement (%)	Comments from experts
8.2 Do you do volunteer work?	6/10	60%	Just find out if they were doing this before. I am not sure how much volunteer work is being done and if it is really part of everyday life for many, therefore exclude this item. If they are working whether full time or part time or voluntary there is no need to single volunteer work out. I think you had a question on whether they are working or not- you can expand on that in a bracket Write like others…"are you able to…"

APPENDIX 4.8

THE NOMINAL GROUP TECHNIQUE MEETING 1 RESULTS

Domain 2: HOME AND FAMILY RESPONSIBILITIES (18 items)

Table 4.34: Nominal Group Meeting 1, Domain 2

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
2.1 Are you able to clean your house?	Yes	Females: Yes Males: No	Females: Yes Males: No	The female participant cleans at least 1-2x in a week Males did not do this task before
2.2 Are you able to clean your yard i.e. pick up papers?	Yes	Yes	Yes	It is difficult to get up from kneeling/stooping
2.3 Are you able to work in your garden or fields e.g. plough, plant flowers, mow the lawn, cut trees, and take the weed out?	Yes	Females: Yes Males: No	Males: No Females: Yes	If you have a garden
2.4 Are you able to cook and prepare meals for your family?	Yes	Females: Yes Males: No	Females: Yes Males: No	Gender specific/ same for rural cohort
2.5 Are you able to cook on the stove/ground fire?	Yes	Females: Yes Males: No	Females: Yes Males: No	Gender specific / same for **rural cohort** **Urban cohort** do not prepare fire therefore inappropriate
2.6 Are you able to wash the dishes?	Yes	Females: Yes Males: No	Females: Yes Males: No	Gender specific/ same for **rural cohort**
2.7 Are you able to wash the clothes?	Yes	Females: Yes Males: No	Females: Yes Males: No	Gender specific/ same for **rural cohort**
2.8 Are you able to hang the clothes on a washing line?	Yes	Females: Yes Males: No	Females: Yes Males: No	Gender specific/ same for **rural cohort**
2.9 Are you able to iron the clothes?	Yes	Females: Yes Males: No	Females: Yes Males: No	Gender specific/ same for **rural cohort**
2.10 Are you able to sew or knit?	Yes	Females: Yes Males: No	Females: Yes Males: No	Gender specific/ same for rural cohort
2.11 Are you able to take care of your livestock e.g. feed your dogs or walk them or shepherd your cattle/ goats?	Yes	Males: Yes Females: No	Males: Yes Females: No	Not applicable in **urban setting**. **Rural cohort** applicable only if one has livestock.

Table 4.34 continued

2.12 Are you able to milk cows?	Yes	No	No	In **urban setting,** inappropriate. **Rural cohort** applicable only if you have livestock.
2.13 Are you able to collect firewood, chop and prepare fire?	Yes	Female in the rural: Yes Females in the urban: No Males in both: No	Female in the rural: Yes Females in the urban: No Males in both: No	In **urban setting** inappropriate **Rural cohort** applicable to female participants only
2.14 Are you able to mud your floor with cow dung or soil?	Yes	Female in the rural: Yes Females in the urban: No Males in both: No	Female in the rural: Yes Females in the urban: No Males in both: No	In **urban setting** inappropriate **Rural cohort** applicable to the female participants
2.15 Are you able to collect water from the river/communal tap?	No	Yes	Yes	Rather say "from a tap outside your yard than communal tap, this could be put in the previous domain under the hand function
2.16 Are you able to grind the mealies?	Yes	No	No	Not applicable in **urban setting.** Not even applicable to the **rural cohort** anymore.
2.17 Are you able to teach your children/grandchildren culturally appropriate home tasks like mudding with cow dung?	Yes	No	No	It is not task that is commonly done in both setting, therefore inappropriate for **both setting.**
2.18 Are you able to take care of your children or grandchildren with regards to their basic needs e.g. bath them, drop and collect from school?	Yes	No	No	Must take care of me now culturally inappropriate, too many questions are applicable to people in **rural areas** and women

Domain 3: COMMUNITY AND SOCIAL RESPONSIBILITIES (6 items)

Table 4.35: Nominal Group Meeting 1, Domain 3

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
3.1 Are you able to attend social events in your community such as funerals, parties or weddings?	Yes	Yes	Yes	None
3.2 Are you able to attend burial society or social club meetings in your community?	Yes	Yes	Yes	None
3.3 Are you able to carry out your community leadership roles e.g. preaching or evangelizing to people or burying your congregates?	Yes	Yes	Yes	None
3.4 Are you able to assist with the digging of a grave in your community?	Yes	Urban: No Rural: Yes	Urban: No Rural: Yes	Not applicable in **urban setting**
3.5 Are you able to attend meetings as called by the chief/Induna or councillor of your village/area?	Yes	Yes	Yes	None
3.6 Are you able to attend other community structures meeting e.g. community policing forum and school governing body?	No	Yes	Yes	The word: "structure" had to be explained first

Domain 4: RELIGION (2 items)

Table 4.36: Nominal Group Meeting 1, Domain 4

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
4.1 Are you able to attend church/religious/spiritual and other church related activities e.g. bible studies, home cell meetings?	Yes	Yes	Yes	None
4.2 Are you able to attend the Thursday or Wednesday prayer meetings at church?	Yes	Same as 4.1	Same 4.1	These are related activities, participants felt this is a very important activity as all were very religious.

Domain 5: EDUCATION (2 items)

Table 4.37: Nominal Group Meeting 1, Domain 5

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
5.1 Are you able to attend school or training programmes in or out of your community? "Adult education included"	Yes	No	No	All participants felt they had gone past a schooling age, but other who get stroke when they are young could still want to go to school hence they chose possibly include option
5.2 Are you able to help train others in activities such as cultural/traditional cooking, acting, or coaching a sport?	Yes	No	No	It is not task that is commonly done in **both setting**.

Domain 6: RELATIONSHIPS (4 items)

Table 4.38: Nominal Group Meeting 1, Domain 6

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
6.1 Are you able to be intimate with your spouse/partner?	No	Yes	Rural: No Urban: Yes	Difficult question and inappropriate to discuss with older people The **urban participants** were shocked and uncomfortable with Q6.1 and Q6.2, as this a topic that is not discussed with a person as young as I am but felt that this is my job they let me ask these two questions anyway. **Rural cohort** shared the same sentiments as the urban with regards to Q 6.1 and 6.2
6.2 Are you able to interact and relate generally to people of the opposite sex/same sex?	No	No	No	Not related to community reintegration The participants were shocked and uncomfortable with Q6.1 and Q.6,2 as this a topic that is not discussed with a person as young as I am but felt that this is my job they let me ask these two questions anyway **Rural cohort** shared the same sentiments as the **urban** with regards to Q 6.1 and 6.2
6.3 Are you able to physically assist other people?	Yes	No	Yes	Need to be specific as they themselves need varying assistant from their family members.
6.4 Are you worried about your appearance when out in public?	Yes	Yes	Yes	None

Domain 7: TRAVEL/TRANSPORT (4 items)

Table 4.39: Nominal Group Meeting 1, Domain 7

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
7.1 Are you able to collect your medication from the nearest clinic or hospital?	Yes	Yes	Yes	None
7.2 Are you able to drive?	Yes	Yes	Yes	Depends- if one drove before. All **rural cohorts** had not driven before stroke. Rather ask if I am able to use the transport I was using before stroke.
7.3 Are you able to get into a taxi or car or bus or train or donkey cart?	Yes	Yes	Yes	Similar to 7.2, can be one question
7.4 Are you able to get to the clinic/hospital for rehabilitation?	Yes	Yes	Yes	Similar to 7.1

Domain 8: RECREATION AND LEISURE (6 items)

Table 4.40: Nominal group meeting 1, domain 8

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
8.1 Are you able to listen to a radio?	Yes	Yes	Yes	Important, need to be kept abreast especially that they are unable to go out
8.2 Are you able to watch TV?	Yes	Yes	Yes	None
8.3 Are you able to read a book or a bible?	Yes	Rural: No Urban: Yes		All the **rural cohort** could not read nor write.
8.4 Are you able to play sport e.g. soccer/netball in your community?	Yes	No	No	Inappropriate especially in **rural areas.**
8.5 Are you able to help train others in activities such as cultural/ traditions cooking and dancing, acting, coaching a sport?	Yes	No	No	Same as 4.2
8.6 Are you able to get out of the house to go shopping in town, going out with friends to watch a movie, go to a night club, watch a soccer match at a stadium?	Yes	Yes	Yes	None

Domain 9: PRODUCTIVITY (3 item)

Table 4.41: Nominal Group Meeting 1, Domain 9

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
9.1 Are you working or intending to return to work?	No	Yes	Yes	Too many questions. It depends on the kind of a job you were doing before stroke if it was a manual job, it may be difficult but you could use your experience to teach others but if educated you could return to work.
9.2 Are you able to do volunteer work in your community?	No	Urban: No Rural: Yes	Yes	The word "volunteer" had to be explained first. Volunteering is a big issue in the rural areas/villages.
9.3 Are you able to take part in your community development projects?	No	Yes	Yes	None

APPENDIX 4.9

THE NOMINAL GROUP TECHNIQUE MEETING 2 RESULTS

Domain 2: HOME AND FAMILY RESPONSIBILITIES (11 items)

Table 4.43: Nominal Group Meeting 2, Domain 2

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
2.1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?	Yes	Yes	Yes	None
2.2 Are you able to work in your garden or fields?	Yes	Yes	Yes	None
2.3 Are you able to collect firewood, chop and prepare fire?	Yes	Yes	Yes	Though still applicable to **rural** female participants.
2.4 Are you able to cook and prepare meals for your family?	Yes	Yes	Yes	Though still applicable more to female participants in **both setting.**
2.5 Are you able to clean the area and utensils used for preparing meals?	Yes	Yes	Yes	None
2.6 Are you able to wash the clothes?	Yes	Yes	Yes	Applicable to female participants.
2.7 Are you able to hang the clothes on a washing line or are you able to dry your clothes they way you have always done?	Yes	Yes	Yes	Applicable to female participants.
2.8 Are you able to collect water from the river/ tap outside?	Yes	Yes	Yes	None
2.9 Are you able to carry heavy object(s) for example shopping bags (2-3)?	Yes	Yes	Yes	None
2.10 Are you able to take care of your livestock (if you have) e.g. feed your dogs or herd/tend your cattle/ goats, including milking?	Yes	Yes	Yes	However, more applicable to male participants in **both setting.**
2.11 Are you able to teach children home keeping tasks e.g. cultural/traditional cooking, and mudding with cow dung?	Yes	Yes	Yes	None

Domain 3: COMMUNITY AND SOCIAL RESPONSIBILITIES (4 items)

Table 4.44: Nominal Group Meeting 2, Domain 3

Item	Is the item clear and understandable"?	Is it important for community reintegration?	Is it culturally/ contextually appropriate?	Comment
3.1 Are you able to attend social events in your community such as funerals, parties or weddings?	Yes	Yes	Yes	None
3.2 Are you able to attend burial society, social club meetings and other structures meeting or meetings called by the chief/councilor in your community?	Yes	Yes	Yes	None
3.3 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregates,?	Yes	Yes	Yes	None
4.1 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?	Yes	Yes	Yes	None

Domain 4: RELATIONSHIPS (9 items)

Table 4.45: Nominal Group Meeting 2, Domain 4

Item	Question clear?	Important for community reintegration?	Appropriateness and comment
4.1 Are you able to be intimate with your spouse/ partner?	Yes	Yes	But still a problem in the **rural cohort**
4.2 Are you able to interact with and relate generally to people?	Yes	Yes	Yes
4.3 Are you worried about your appearance when out in public?	Yes	Yes	Yes
4.4 Are you able to communicate with your family?	Yes	Yes	Yes
4.5 Or people in your area?			
4.6 Are your family and friends visiting you at home?	Yes	Yes	Yes
4.7 Are you able to accept help and support from your family and friends?	Yes	Yes	Yes
4.8 Are you able to solve problems with family and friend's problems	Yes	Yes	Yes
4.9 Are you able to assist others people e.g. help someone get up, help someone with poor balance?	Yes	Yes	Yes

Domain 5: TRAVEL/ TRANSPORT (3 items)

Table 4.46: Nominal Group Meeting 2, Domain 5

Item	Question clear?	Important for community reintegration?	Appropriateness culturally and contextually?	Comments
5.1 Are you able to get to the clinic/hospital to collect your medication or for rehabilitation/nursing/ medical help?	Yes	Yes	Yes	None
5.2 Are your friends and family assisting you with your travelling needs?	Yes	Yes	Yes	None
5.3 Are you able to use the same transport you used before the stroke?	Yes	Yes	Yes	None

Domain 6: RECREATION AND LEISURE (3 items)

Table 4.47: Nominal Group Meeting 2, Domain 6

Item	Question clear?	Important for community reintegration?	Appropriateness culturally and contextually?	Comments
6.1 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?	Yes	Yes	Yes	None
6.2 Are you able to do a physical activity such as playing any sport?	Yes	Yes	Yes	None
6.3 Are you able to get out of the house to go shopping in town or going out with friends or watch a soccer match at a stadium?	Yes	Yes	Yes	None

Domain 7: WORK AND EDUCATION (2 items)

Table 4.48: Nominal Group Meeting 2, Domain 7

Item	Question clear?	Important for community reintegration?	Appropriateness culturally and contextually?	Comments
7.1 Are you able to go back to work (paid or volunteer)?	Yes	Yes	Yes	None
7.2 Are you able to attend school or training programmes (including adult education) in or out of your community?	Yes	Yes	Yes	None

Domain 8: PSYCHOLOGICAL ADJUSTMENT/COPING (3 item)

Table 4.49: Nominal group meeting 2, domain 8

Item	Question clear?	Important for community reintegration?	Appropriateness culturally and contextually?
8.1 Are you hopeful that you will get better?	Yes	Yes	Yes
8.2 Are you able to remember things told and events easily?	Yes	Yes	Yes
8.3 Are you able to make decisions regarding your life and family issues?	Yes	Yes	Yes

APPENDIX 4.10

THE FINAL PRODUCT DELPHI ROUND 3: ENGLISH VERSION OF THE NEWLY DEVELOPED OUTCOME MEASURE

COMMUNITY REINTEGRATION MEASURE (44 items)

Name:	**Age:**	
Gender:	**Race:**	**Rural/Urban:**
Level of formal education obtained:	**Current employment status:**	
Occupation (current or previous):	**Marital status:**	
Do you have a caregiver: Yes or No	**Date of stroke:**	
Side of hemiplegia:	**Name of the interviewer:**	
Date of the interview:	**Location of the interview:**	
Who was interviewed?	**Patient or caregiver?**	
Physical address of the patient including telephone numbers:		
How long have you been living in this community before and after stroke?		
Baseline assessment:	**Follow up assessment:**	

Instructions to the patient:

I am going to read the following questions about your stroke to you, please respond accordingly.

1. **ACTIVITIES OF DAILY LIVING AND PERSONAL CARE (9 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1.1 Are you able to get up and out of bed in the morning?				
1.2 Are you able to pour water into a kettle/basin?				
1.3 Are you able to wash yourself?				
1.4 Are you able to dress yourself?				
1.5 Are you able to feed yourself?				
1.6 Are you able to drink from a cup or glass?				
1.7 Are you able to write or draw a cross?				
1.8) Are you able to move around uneven/hilly areas?				
1.9 Are you able to move around in your? a) Home,				
b) Yard				
c) Community?				

2. **HOME AND FAMILY RESPONSIBILITIES (11 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
2.1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?				
2.2 Are you able to work in your garden or fields?				
2.3 Are you able to collect firewood, chop and prepare fire?				
2.4 Are you able to cook and prepare meals for your family?				
2.5 Are you able to clean the area and utensils used for preparing meals?				
2.6 Are you able to wash the clothes?				
2.7 Are you able to hang the clothes on a washing line or are you able to dry your clothes the way you have always done?				
2.8 Are you able to collect water from the river/tap outside?				
2.9 Are you able to carry heavy object(s) for example shopping bags (2-3 maximum)?				
2.10 Are you able to take care of your livestock (if you have) e.g. feed your dogs or herd/tend your cattle/ goats, including milking?				
2.11 Are you able to teach children home keeping tasks e.g. cultural/traditional cooking, and mudding with cow dung?				

3. **COMMUNITY AND SOCIAL RESPONSIBILITIES (4 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
3.1 Are you able to attend social events in your community such as funerals, parties or weddings?				
3.2 Are you able to attend burial society, social club meetings and other structures meeting or meetings called by the chief/councilor in your community?				
3.3 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregants,?				
4.1 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?				

4. **RELATIONSHIPS (9 items)**

Since your stroke, please rate your satisfaction with how you relate to yourself and others on a scale of 0-2:

Item	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)
4.1 How satisfied are you with your intimacy with spouse?			
4.2 How satisfied are you with your interaction with other people?			
4.3 How satisfied are you with your appearance in public?			
4.4 How satisfied are you with your communication with family?			
4.5 How satisfied are you with your communication with people around you?			
4.6 How satisfied are you with your visitors?			
4.7 How satisfied are you with help and support that you receive from your family and friends?			
4.8 How satisfied are you with your ability to solve family and friend's problems			
4.9 How satisfied are you with your ability to physically assist someone?			

5. **TRAVEL/ TRANSPORT (3 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
5.1 Are you able to get to the clinic/hospital to collect your medication or for rehabilitation/nursing/ medical help?				
5.2 Are your friends and family assisting you with your travelling needs?				
5.3 Are you able to use the same transport you used before the stroke?				

6. **RECREATION AND LEISURE (3 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
6.1 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?				
6.2 Are you able to do a physical activity such as playing any sport?				
6.3 Are you able to get out of the house to go shopping in town or going out with friends or watch a soccer match at a stadium?				

7. **WORK AND EDUCATION (2 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
7.1 Are you able to go back to work (paid or volunteer)?				
7.2 Are you able to attend school or training programmes (including adult education) in or out of your community?				

8. **PSYCHOLOGICAL ADJUSTMENT/COPING (3 item)**

Since your stroke:

Item			
8.1 Are you hopeful that you will get better?	Not at all (0)	Somewhat (1)	Definitely (2)
8.2 Are you able to easily remember things told and events?	Not at all (0)	To some extent (1)	To a full extent (2)
8.3 Are you able to make decisions regarding your life and family issues?	Not at all (0)	To some extent (1)	To a full extent (2)

APPENDIX 5.1

CHAPTER 5 APPENDICES: FACTOR ANALYSIS INFORMATION SHEET FOR PATIENTS AND CAREGIVERS IN STUDY 2, PHASE 2

Hello my name is Douglas Maleka; I am a post-graduate student registered for PhD at the University of the Witwatersrand in Johannesburg, in the Faculty of Health Sciences, School of Therapeutic Sciences-Department of Physiotherapy.

The title of this study is “Development of an outcome measure to assess community reintegration following stroke living in poor socioeconomic rural and urban areas of South Africa”

The main aim of the study is:

> To develop and validate an outcome measure to assess community reintegration following stroke living in poor socioeconomic rural and urban areas of South Africa

An outcome measure is a rating scale that will give an indication of how well you have settled in your community. The outcome measure will assist you, your family and your therapists in developing plans for your rehabilitation in the community to make you settle well into your community.

The researcher would like to invite you to take part in a study that is already continuing, at this stage an outcome measure has been developed and need to still reduce more of the items that are contained in this OM.

By taking part in this study you will possibly be assisting yourself and other people who have stroke, in that the information obtained may be used to plan for community-based rehabilitation treatment. There are no risks associated with this whole process of research.

Taking part is optional, and refusal to participate will not affect your management at the clinic in any way. If you wish to leave the study at any time, you may do so, also without affecting any treatment that you get at the clinic.

What you say will be kept in secret by the researchers in this interview but whether other members of the group will do the same cannot be certain. Your name will not be used on any of the information used in this study.

A copy of the results of the study will be made available to your on request, as soon as the write up is complete and has been approved.

If you agree to take part in the study will you please sign a consent form below.

Thanking you, Mr Douglas Maleka, Physiotherapist

APPENDIX 5.2

CONSENT FORM TO TAKE PART IN FACTOR ANALYSIS PHASE FOR PATIENTS AND CAREGIVERS, STUDY 2, PHASE 2

I have read and understood the contents of the information sheet. I therefore consent to participate in the factor analysis phase of this study.

Patient and caregivers names:

Signature:

APPENDIX 5.3

AN EXAMPLE OF THE ENGLISH VERSION OF THE NEWLY DEVELOPED OUTCOME MEASURE USED IN THE FACTOR ANALYSIS FOR DATA COLLECTION

COMMUNITY REINTEGRATION TOOL

Name:	**Age:**
Gender:	**Race:**
Level of formal education obtained:	**Current employment status:**
Occupation (current or previous):	**Marital status:**
Do you have a caregiver: Yes or No	**Date of CVA:**
Side of hemiplegia:	**Name of the interviewer:**
Date of the interview:	**Location of the interview:**
Who was interviewed?	**Patient or caregiver?**
Physical address of the patient including telephone numbers:	
How long have you been living in this community?	

Instructions to the patient:

I am going to read the following questions to you, please respond accordingly.

1. **ACTIVITIES OF DAILY LIVING AND PERSONAL CARE (9 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1.1 Are you able to get up and out of bed in the morning?				
1.2 Are you able to pour water into a kettle/basin?				
1.3 Are you able to wash yourself?				
1.4 Are you able to dress yourself?				
1.5 Are you able to feed yourself?				
1.6 Are you able to drink from a cup or glass?				
1.7 Are you able to write or draw a cross?				
1.8) Are you able to move around uneven/hilly areas?				
1.9 Are you able to move around in your? a) Home,				
b) Yard				
c) Community?				

2. **HOME AND FAMILY RESPONSIBILITIES (11 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
2.1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?				
2.2 Are you able to work in your garden or fields?				
2.3 Are you able to collect firewood, chop and prepare fire?				
2.4 Are you able to cook and prepare meals for your family?				
2.5 Are you able to clean the area and utensils used for preparing meals?				
2.6 Are you able to wash the clothes?				
2.7 Are you able to hang the clothes on a washing line or are you able to dry your clothes the way you have always done?				
2.8 Are you able to collect water from the river/communal tap?				
2.9 Are you able to carry heavy object(s) for example shopping bags (2-3)?				
2.10 Are you able to take care of your livestock (if you have) e.g. feed your dogs or herd/tend your cattle/ goats, including milking?				
2.11 Are you able to teach children home keeping tasks e.g. cultural/traditional cooking, and mudding with cow dung?				

3. **COMMUNITY AND SOCIAL RESPONSIBILITIES (4 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
3.1 Are you able to attend social events in your community such as funerals, parties or weddings?				
3.2 Are you able to attend burial society, social club meetings and other structures meeting or meetings called by the chief/councilor in your community?				
3.3 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregants,?				
3.4 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?				

4. **RELATIONSHIPS (10 items)**

Since your stroke, please rate your satisfaction with how you relate to yourself and others on a scale of 0-2:

Item	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)
4.1 How satisfied are you with your intimacy with spouse?			
4.2 How satisfied are you with your interaction with other people?			
4.3 How satisfied are you with your appearance in public?			
4.4 How satisfied are you with your communication with family?			
4.5 How satisfied are you with your communication with people around you?			
4.6 How satisfied are you with your visitors?			
4.7 How satisfied are you with help and support that you receive from your family and friends?			
4.8 How satisfied are you with your ability to solve family and friend's problems			
4.9 How satisfied are you with your ability to physically assist someone?			

5. **TRAVEL/ TRANSPORT (3 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
5.1 Are you able to get to the clinic/hospital to collect your medication or for rehabilitation/nursing/ medical help?				
5.2 Are your friends and family assisting you with your travelling needs?				
5.3 Are you able to use the same transport you used before the stroke?				

6. **RECREATION AND LEISURE (3 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
6.1 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?				
6.2 Are you able to do a physical activity such as playing any sport?				
6.3 Are you able to get out of the house to go shopping in town or going out with friends or watch a soccer match at a stadium?				

7. **WORK AND EDUCATION (2 items)**

Since your stroke:

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
7.1 Are you able to go back to work (paid or volunteer)?				
7.2 Are you able to attend school or training programmes (including adult education) in or out of your community?				

8. **PSYCHOLOGICAL ADJUSTMENT/COPING (3 item)**

Since your stroke:

Item			
8.1 Are you hopeful that you will get better?	Not at all (0)	Somewhat (1)	Definitely (2)
8.2 Are you able to easily remember things told and events?	Not at all (0)	To some extent (1)	To a full extent (2)
8.3 Are you able to make decisions regarding your life and family issues?	Not at all (0)	To some extent (1)	To a full extent (2)

APPENDIX 5.4

AN EXAMPLE OF THE SESOTHO VERSION OF THE NEWLY DEVELOPED OUTCOME MEASURE USED IN THE FACTOR ANALYSIS FOR DATA COLLECTION

DINTLHA TSA BOPHELO BA HAO

Lebitso:	**Dilemo:**
Bong:	**Morabe:**
Boiphitlhelo ba tsa thuto:	**Maemo a mosebetsi ha jwale:**
Mosebetsi (wa jwale kapa o fetileng):	**Maemo a lenyalo:**
Mohlokomedi: (ya katisitsweng kampo tjhee):	**Letsatsi la ho swa lehlakore:**
Lehlakore le le shweleng:	**Lebitso la mohlahlobi:**
Letsatsi la dipotso:	**Sebaka moo ho boditsweng dipotso:**
Ke mang a botsitsweng dipotso?	**Mokudi kapa Mohlokomedli**
Aterese ya mokudi ho kenyelletsa le dinomoro tsa mohala:	
O nale sebaka se se kakang o dula mona?	

Ditaelo ho mokudi:

Ke tIo ho balla dipotso tse latelang, mme ke kopa o arabe ho ya ka moo ho lokelang.

1. **DIKETSAHALO TSA BOPHELO BA LETSATSI LE LETSATSI LE KGATHALLO YA BOTHO (dinthla tse 9)**

Ho tloha o shwele letlhakore:

Ntlha	**Tjhee (0)**	**Ke gona ka thuso e kgolo (1)**	**Ke gona ka thusenyana (2)**	**Ke gona ka ntle le thuso (3)**
1.1 Na o kgona ho tsoha, le ho tswa malaong hoseng?				
1.2. O gona ho tshela metsi ka ketleleng kapa sekotlolong sa ho hlapela?				
1.3 O gona ho itlhapisa?				
1.4 O gona ho ikapesa?				
1.5 O gona ho itjesa?				
1.6 O gona ho inwesa ka galase kapa lebekere?				
1.7 O gona ho ngola kapa ho taka sefapano?				
1.8) O gona ho itsamaisa ditulong tse nang le makukuno le moepa?				
1.9 O gona ho itsamaisa dutolng tse latelang? a) Hae				
b) Jareteng ya hao?				
c) Setjhabeng?				

2. **MAIKARABELO A LELAPA LE KA TLUNG (dintlha tse 11)**

Ho tloha o shwele letlhakore:

Ntlha	**Tjhee (0)**	**Ke gona ka thuso e kgolo (1)**	**Ke gona ka thusonyana (2)**	**Ke gona ka ntle le thuso (3)**
2.1 O gona ho hlwekisa ntlo ya hao kapa jarete, ke hore ho fiela, ho thonapa dipampiri le/kapa ho dila ka moswang?				
2.2 O gona ho sebetsa tshimong kapa serapeng?				
2.3 O gona ho bokella patsi, ho e ratha le ho besa?				
2.4 O gona ho pheha le ho lokisa dijo bakeng sa lelapa la hao?				
2.5 O gona ho hlwekisa tulo ya ho lokisa dijo le disebediswa tsa ho pheha?				
2.6 O gona ho hlatswa diaparo?				
2.7 O gona ho aneha diaparo terateng kapa ho di omisa kamoo o neng o gona pele?				
2.8 O gona ho kga metsi Sedibeng?				
2.9 O gona ho kuka dintho tse boima, jwalo ka mekotla ya mabenkeleng (2-3)?				
2.10 O gona ho hlokomela mehlape (haeba o na le yona)? Mohlala, ho fepa dintja, ho diisa dikgomo/dipudi, hokenyelletsa ho hama?				
2.11 O gona ho ruta bana mesebetsi ya ntlo, jwalo ka ho pheha ha setso, ho dila ka moswang?				

3. **MAIKARABELO A SETJHABENG (Dintlha tse 3)**

Ho tloha o shwele letlhakore:

Ntlha	Tjhee (0)	Ke gona ka thuso e kgolo (1)	Ke gona ka thusonyana (2)	Ke gona ka ntle le thuso (3)
3.1 O gona ho tsamay mekete ya setjhaba jwalo ka mafu, meketjana le manyalo?				
3.2 O gona ho tsamaya di-burial society, dikopano tsa social clubs le dikopano tse ding tsa setjhaba tse bitswang ke morena/lekhanselara?				
3.3 O gona ho bapala karolo ya hao mesebetsing ya setjhaba, jwalo ka ho binela khwaere, ho thusa sekolo sa motse, ho tjhepa mabitla, boetapele ba setjhaba, ho rera kapa ho pata bafu?				
3.1 O gona ho tsamaya diketsahalo tsa semoya, jwalo ka dithuto tsa Bibele, Home Cell le dikopano tsa thapelo?				

4. DIKAMANO (Dintlha tse 8)

Ho tloha o shwele letlhakore ke kopa o bontshe ka moo o kgotsofetseng ka teng ka bowena le batho ba bangwe mo sekalong sa 0-2:

Ntlha	Ha key a kgotsofala	Ke kgotsofetse	Ke kgotsofetse thata
4.1 O gona ho teba dikamanong tsa hao le molekane wa hao?			
4.2 O gona ho amana le batho ba bang?			
4.3 Ekaba o tshwenyehile ka sebopeho sa hao ha o le tulong tsa setjhaba?			
4.4 O gona ho buisana le maloko a lelapa la hao?			
4.5 Kapa batho ba dulang tulong ya hao?			
4.6 Ekaba metswalle le ba lelapa ba o etela ha hao?			
4.7 O gona ho amohela thuso le tshehetso, ho kenyelletsa ya maikutlo ho tswa ho metswalle le lelapa?			
4.8 O gona ho rarolla mathata le metswalle le ba lelapa?			
4.9 O gona ho thusa batho ba bang, jwale ka ho ba tsosa, ho thusa motho ya hlokang ho tshehetswa?			

5. **BOETI/BOTSAMAI (Dintlha tse 3)**

Ho tloha o shwele letlhakore:

Ntlha	Tjhee (0)	Ke gona ka thuso e kgolo (1)	Ke gona ka thusonyana (2)	Ke gona ka ntle le thuso (3)
5.1 O gona ho ya kliniking/sepetlele ho lata meriana kapa bakeng sa thuso ya bophelo bo bottle?				
5.2 Ekaba ba lelapa le metswalle ba o thusa ka dithuso tsa ho tsamaya?				
5.3 O gona ho sebedisa dipalangwa tseo o neng o di sebedisa pele?				

6. **BOITHABISO (Dintlha tse 3)**

Ho tloha o shwele letlhakore:

Ntlha	Tjhee (0)	Ke gona ka thuso e kgolo (1)	Ke gona ka thusonyana (2)	Ke gona ka ntle le thuso (3)
6.1 O gona ho nka karolo dinthong tse tlisang boithabiso kapa ho phomola, tse jwalo ka ho mamela radio, ho shebella TV kapa ho bala buka/Bibele/dikuranta/mag azine?				
6.2 O gona ho nka karolo dinthong tse hlokang ho sebediswa ha mmele, jwalo ka dipapadi?				
6.3 O gona ho tswa ho ya mabenkeleng kapa ho tswa le metswalle kapa ho shebella papadi ya bolo lebaleng la dipapadi?				

7. **MOSEBETSI LE THUTO (Dintlha tse 2)**

Ho tloha o shwele letlhakore:

Ntlha	Tjhee (0)	Ke gona ka thuso e kgolo (1)	Ke gona ka thusonyana (2)	Ke gona ka ntle le thuso (3)
7.1 O gona ho kgutlela mosebetsing (o patalwang kapa wa boinehelo)?				
7.2 O gona ho ya sekolong kapa di-progama tsa thuto (ho kenyelletsa le thuto ya batho ba baholo) setjhabeng sa heno?				

8. **HO LOKA KELELLONG/HO GONA (Dintlha tse 3)**

Ho tloha o shwele letlhakore:

Ntlha			
8.1 O na le tshepo ya ho ba betere?	Tjhee (0)	Mohlomong (1)	Ee (2)
8.2 O gona ho hoopla dintho le diketsahalo ha bobebe?	Tjhee (0)	Ho fitlha mo horileng (1)	Kaofela (2)
8.3 O gona ho nka diqeto bakeng sa bophelo ba hao le mabaka a lelapa?	Tjhee (0)	Ho fitlha mo horileng (1)	Kaofela (2)

APPENDIX 5.5

EXCESSIVE TABLES FROM THE FIRST INTERNAL CONSISTENCY

Domain 2: HOME AND FAMILY RESPONSIBILITIES

Table 5.9: Internal Consistency for Domain Two: Home and Family Responsibilities for the Urban Cohort (n=112)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D2Q1	112	0.76	0.89
D2Q2	112	0.65	0.90
D2Q3	112	0.64	0.94
D2Q4	112	0.76	0.89
D2Q5	112	0.73	0.90
D2Q6	112	0.74	0.89
D2Q7	112	0.76	0.89
D2Q8	112	0.55	0.90
D2Q9	112	0.68	0.92
D2Q10	112	0.54	0.90
D2Q11	112	0.44	0.91
Test scale			0.91

Table 5.10: Internal Consistency for Domain Two: Home and Family Responsibilities for the Rural Cohort (n=104)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D2Q1	104	0.77	0.88
D2Q2	104	0.63	0.85
D2Q3	104	0.63	0.89
D2Q4	104	0.81	0.88
D2Q5	104	0.78	0.88
D2Q6	104	0.73	0.88
D2Q7	104	0.72	0.89
D2Q8	104	0.55	0.89
D2Q9	104	0.64	0.89
D2Q10	104	0.48	0.90
D2Q11	104	0.28	0.91
Test scale			0.90

Domain 3: COMMUNITY AND SOCIAL RESPONSIBILITIES

Table 5.11: Internal Consistency for Domain Three: Community and Social Responsibility for the Urban Cohort (n=112)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D3Q1	112	0.86	0.90
D3Q2	112	0.90	0.88
D3Q3	112	0.85	0.90
D3Q4	112	0.73	0.94
Test scale			0.93

Table 5.12: Internal Consistency for Domain Three: Community and Social Responsibility for the Rural Cohort (n=104)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D3Q1	104	0.81	0.83
D3Q2	104	0.87	0.81
D3Q3	104	0.62	0.90
D3Q4	104	0.71	0.87
Test scale			0.88

Domain 4: RELATIONSHIPS

Table 5.13: Internal Consistency for Domain Four: Relationship for the Urban Cohort (n=112)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D4Q1	112	0.26	0.86
D4Q2	112	0.71	0.82
D4Q3	112	0.50	0.84
D4Q4	112	0.70	0.82
D4Q5	112	0.72	0.82
D4Q6	112	0.57	0.83
D4Q7	112	0.50	0.84
D4Q8	112	0.70	0.82
D4Q9	112	0.47	0.84
Test scale			0.85

Table 5.14: Internal Consistency for Domain Four: Relationship for the Rural Cohort (n=104)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D4Q1	104	0.36	0.87
D4Q2	104	0.76	0.40
D4Q3	104	0.71	0.84
D4Q4	104	0.72	0.84
D4Q5	104	0.71	0.84
D4Q6	104	0.57	0.86
D4Q7	104	0.63	0.85
D4Q8	104	0.73	0.84
D4Q9	104	0.28	0.88
Test scale			0.87

Domain 5: TRAVEL AND TRANSPORT

Table 5.15: Internal Consistency for Domain Five: Travel and Transport for the Urban Cohort (n=112)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D5Q1	112	0.83	0.76
D5Q2	112	0.67	0.90
D5Q3	112	0.79	0.80
Test scale			0.87

Table 5.16: Internal Consistency for Domain Five: Travel and Transport for the Rural Cohort (n=104)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D5Q1	104	0.66	0.54
D5Q2	104	0.54	0.69
D5Q3	104	0.51	0.72
Test scale			0.74

Domain 6: RECREATION AND LEISURE

Table 5.17: Internal Consistency for Domain Six: Recreation and Leisure for the Urban Cohort (n=112)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D6Q1	112	0.51	0.81
D6Q2	112	0.65	0.67
D6Q3	112	0.70	0.61
Test scale			0.78

Table 5.18: Internal Consistency for Domain Six: Recreation and Leisure for the Rural Cohort (n=104)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D6Q1	104	0.20	0.65
D6Q2	104	0.40	0.34
D6Q3	104	0.45	0.25
Test scale			0.53

Domain 8: PSYCHOLOGICAL ADJUSTMENT/COPING

Table 5.19: Internal Consistency for Domain Eight: Psychological Adjustment/Coping for the Urban Cohort (n= 112)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D8Q1	112	0.52	0.85
D8Q2	112	0.75	0.62
D8Q3	112	0.68	0.69
Test scale			0.80

Table 5.20: Internal Consistency for Domain Eight: Psychological Adjustment/Coping for the Rural Cohort (n=104)

Item number	Number of observations	Item-rest correlation	Cronbach Alpha
D8Q1	104	0.49	0.76
D8Q2	104	0.65	0.57
D8Q3	104	0.59	0.64
Test scale			0.75

APPENDIX 5.6

EXCESSIVE TABLES FROM FACTOR ANALYSIS

FACTOR II

Table 5.23: Rotated Factor Loadings for Factor II for The Urban Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq2-1		0.3997	0.4412					
Dq2-2		0.3074						
Dq2-3		-				0.6494		
Dq2-4		-	0.6683					
Dq2-5		-	0.6817					
Dq2-6		-	0.8575					
Dq2-7		-	0.8386					
Dq2-8	0.5764	-						
Dq2-9	0.3206	-						
Dq2-10		-				0.8582		
Dq2-11						0.8995		

Table 5.24: Rotated Factor Loadings for Factor II for the Rural Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq2-1	0.5206	-					0.4831	
Dq2-2	0.5695	-					0.3825	
Dq2-3	0.4474	-						
Dq2-4	0.8401	-						
Dq2-5	0.8190	-						
Dq2-6	0.9148	-						
Dq2-7	0.8430	-						
Dq2-8	0.6983	-					0.4788	
Dq2-9	0.5020	-						
Dq2-10		-				0.3352	0.3651	
Dq2-11		-				0.5918		

FACTOR III

Table 5.25: Rotated Factor Loadings for Factor III for the Urban Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq3-1		0.7836	-					
Dq3-2		0.8860	-					
Dq3-3		0.8167	-					
Dq3-4		0.5134	-					

Table 5.26: Rotated Factor Loadings for Factor III for the Rural Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq3-1		0.9132	-					
Dq3-2		0.9760	-					
Dq3-3		0.7182	-					
Dq3-4		0.6839	-					

FACTOR IV

Table 5.27: Rotated Factor Loadings for Factor IV for the Urban Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq4-1		0.5504		-				0.4084
Dq4-2				0.9574				
Dq4-3		0.3659	0.4205	-				
Dq4-4				-				
Dq4-5				-				
Dq4-6				-	0.6279			
Dq4-7				-	0.8127			
Dq4-8				-	0.6125			
Dq4-9			0.4418	-				

Table 5.28 Rotated Factor Loadings for Factor IV for the Rural Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq4-1				-				
Dq4-2				-	0.8441			
Dq4-3				-	0.6672			
Dq4-4				-	0.8042			
Dq4-5				-	0.8501			
Dq4-6				-	0.7438			
Dq4-7				-	0.6950			
Dq4-8				-	0.6814			
Dq4-9			0.5194	-				0.3386

FACTOR V

Table 5.29: Rotated Factor Loadings for Factor V for the Urban Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq5-1	0.6976				-			
Dq5-2	0.4546				0.4624			
Dq5-3	0.6750				-			

Table 5.30: Rotated Factor Loadings for Factor V for the Rural Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq5-1		0.3059			-			
Dq5-2					-		0.3573	
Dq5-3	0.3323	0.3023			-			

FACTOR VI

Table 5.31: Rotated Factor Loadings for Factor VI for the Urban Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq6-1	0.6772					-		
Dq6-2		0.3532				-		
Dq6-3	0.4120	0.3611				-		

Table 5.32: Rotated Factor Loadings for Factor VI for the Rural Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq6-1				0.5370		-		
Dq6-2						-		0.5194
Dq6-3						-	0.5704	

FACTOR VII

Table 5.33: Rotated Factor Loadings for Factor VII for the Urban Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq7-1							0.9080	
Dq7-2							0.9045	

Table 5.34: Rotated Factor Loadings for Factor VII for the Rural Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq7-1							-	0.5062
Dq7-2							0.7127	

FACTOR VIII

Table 5.35: Rotated Factor Loadings for Factor VIII for the Urban Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq8-1								0.3686
Dq8-2					0.5710			0.3832
Dq8-3					0.5141			0.3388

Table 5.36: Rotated Factor Loadings for Factor VIII for the Rural Setting

Item	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Factor VIII
Dq8-1						0.4851		-
Dq8-2						0.6466		-
Dq8-3					0.3384	0.5149		-

APPENDIX 5.7

NEWLY GROUPED ITEMS FROM FACTOR ANALYSIS

Table 5.37: A Summary of the Newly Grouped Items in Factor I

Urban Setting Version	Rural Setting Version
Factor 1	**Factor 1**
Dq1- 1	Dq2-1
Dq1- 2	Dq2- 2
Dq1- 3	Dq2- 3
Dq1- 4	Dq2- 4
Dq1- 5	Dq2- 5
Dq1- 6	Dq2- 6
Dq1- 8	Dq2- 7
Dq1- 9	Dq2- 8
Dq1- 10	Dq2- 9
Dq1- 11	Dq5- 3
Dq2- 8	
Dq2- 9	
Dq5- 1	
Dq5- 3	
Dq6-1	
Dq6-3	

Table 5.38: A Summary of the Newly Grouped Items in Factor II

Urban Setting Version	Rural Setting Version
Factor 2	**Factor 2**
Dq2- 2	Dq3- 1
Dq3- 1	Dq3- 2
Dq3- 2	Dq3- 3
Dq3- 3	Dq3- 4
Dq3- 4	Dq5- 1
Dq4- 1	
Dq4- 2	
Dq6- 2	

Table 5.39: A Summary of the Newly Grouped Items in Factor III

Urban Setting Version	Rural Setting Version
Factor 3	**Factor 3**
Dq2- 1	Dq1- 2
Dq2- 4	Dq1- 8
Dq2- 5	Dq1- 9
Dq2- 6	Dq1- 10
Dq2- 7	Dq1- 11
Dq4- 3	Dq4- 9
Dq4- 9	

Table 5.40: A Summary of the Newly Grouped Items in Factor IV

Urban Setting Version	Rural Setting Version
Factor 4	**Factor 4**
	Dq1- 1
	Dq1- 3
	Dq1- 4
	Dq1- 5
	Dq1- 6
	Dq1- 7
	Dq6- 1

Table 5.41: A Summary of the Newly Grouped Items in Factor V

Urban Setting Version	Rural Setting Version
Factor 5	**Factor 5**
Dq4- 6	Dq4- 2
Dq4- 7	Dq4- 3
Dq4- 8	Dq4- 4
Dq5- 2	Dq4- 5
Dq8- 2	Dq4- 6
Dq8- 3	Dq4- 7
	Dq4- 8

Table 5.42: A Summary of the Newly Grouped Items in Factor VI

Urban Setting Version	Rural Setting Version
Factor 6	**Factor 6**
Dq2- 3	Dq8- 1
Dq2-10	Dq8- 2
Dq2- 11	Dq8- 3

Table 5.43: A Summary of the Newly Grouped Items in Factor VII

Urban Setting Version	Rural Setting Version
Factor 7	**Factor 7**
Dq7- 1	Dq2- 10
Dq7- 2	Dq5- 2
	Dq6- 3
	Dq7- 2

Table 5.44: A Summary of the Newly Grouped Items in Factor VIII

Urban Setting Version	Rural Setting Version
Factor 8	**Factor 8**
Dq1- 7	Dq6- 2
Dq8-1	Dq2- 11
	Dq7- 1

APPENDIX 5.8

EXCESSIVE TABLES FROM THE INTERNAL CONSISTENCY AFTER THE ITEMS WERE REGROUPED

Table 5.47: Internal Consistency for Factor II Urban Setting Version (n=112)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq2- 2	112	0.59	0.86
Dq3- 1	112	0.82	0.83
Dq3- 2	112	0.84	0.83
Dq3- 3	112	0.77	0.84
Dq3- 4	112	0.71	0.85
Dq4- 1	112	0.30	0.89
Dq4- 2	112	0.42	0.88
Dq6- 2	112	0.64	0.85
Total score			0.87

Table 5.48: Internal Consistency for Factor II Rural Setting Version (n=104)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq3- 1	104	0.80	0.82
Dq3- 2	104	0.88	0.80
Dq3- 3	104	0.62	0.87
Dq3- 4	104	0.69	0.85
Dq5- 1	104	0.55	0.88
Total score			0.87

Table 5.49: Internal Consistency for Factor III Urban Setting Version (n=112)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq2- 1	112	0.76	0.90
Dq2- 4	112	0.81	0.90
Dq2- 5	112	0.82	0.90
Dq2- 6	112	0.77	0.90
Dq2- 7	112	0.78	0.90
Dq4- 3	112	0.59	0.92
Dq4- 9	112	0.71	0.91
Total score			0.92

Table 5.50: Internal Consistency for Factor III Rural Setting Version (n=104)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq1- 2	104	0.68	0.88
Dq1- 8	104	0.82	0.86
Dq1- 9	104	0.85	0.85
Dq1- 10	104	0.91	0.84
Dq1- 11	104	0.86	0.85
Dq4- 9	104	0.25	0.94
Total score			0.89

FACTOR IV URBAN SETTING VERSION

From the factor analysis there were no items for this factor for urban setting.

Table 5.51: Internal Consistency for Factor IV Rural Setting Version (n= 104)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq1- 1	104	0.84	0.88
Dq1- 3	104	0.74	0.89
Dq1- 4	104	0.77	0.88
Dq1- 5	104	0.82	0.88
Dq1- 6	104	0.82	0.88
Dq1- 7	104	0.46	0.92
Dq6- 1	104	0.60	0.90
Total score			0.90

Table 5.52: Internal Consistency for Factor V Urban Setting Version (n=112)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq4- 6	112	0.58	0.85
Dq4- 7	112	0.75	0.82
Dq4- 8	112	0.73	0.82
Dq5- 2	112	0.58	0.85
Dq8- 2	112	0.62	0.84
Dq8- 3	112	0.67	0.83
Total score			0.86

Table 5.53: Internal Consistency for Factor V Rural Setting Version (n= 104)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq4- 2	104	0.80	0.87
Dq4- 3	104	0.70	0.88
Dq4- 4	104	0.77	0.88
Dq4- 5	104	0.75	0.88
Dq4- 6	104	0.60	0.89
Dq4- 7	104	0.65	0.89
Dq4- 8	104	0.68	0.89
Total score			0.90

Table 5.54: Internal Consistency for Factor VI Urban Setting Version (n= 112)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq2- 3	112	0.59	0.87
Dq2-10	112	0.77	0.70
Dq2- 11	112	0.74	0.73
Total score			0.83

Table 5.55: Internal Consistency for Factor VI Rural Setting Version (n= 104)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq8- 1	104	0.49	0.76
Dq8- 2	104	0.65	0.57
Dq8- 3	104	0.59	0.64
Total score			0.75

FACTOR VII URBAN SETTING VERSION

There were only two items in this factor and the overall scale reliability coefficient was 0.91.

Table 5.56: Internal Consistency for Factor VII Rural Setting Version (n=104)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq2- 10	104	0.50	0.58
Dq5- 2	104	0.44	0.62
Dq6- 3	104	0.50	0.58
Dq7- 2	104	0.38	0.65
Total score			0.67

FACTOR VIII FOR URBAN SETTING VERSION

There were only two items in this factor and the overall scale reliability coefficient was 0.49.

Table 5.57: Internal Consistency for Factor VIII Rural Setting Version (n=104)

Item	Number of observation	Item- rest correlation	Cronbach Alpha
Dq6- 2	104	0.21	0.25
Dq2- 11	104	0.10	0.46
Dq7- 1	104	0.31	0.03
Total score			0.35

APPENDIX 5.9

OUTCOME MEASURE: URBAN SETTING VERSION

Domain 1: ADL AND SELF CARE

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to get up and out of bed in the morning?				
2 Are you able to pour water into a kettle/basin?				
3 Are you able to wash yourself?				
4 Are you able to dress yourself?				
5 Are you able to feed yourself?				
6 Are you able to drink from a cup or glass?				
7 Are you able to move around uneven/hilly areas?				
8 Are you able to move around in your home?				
9 Are you able to move around in your yard?				
10 Are you able to move around in your community?				
11 Are you able to collect water from the river/communal tap?				
12 Are you able to carry heavy object(s) for example shopping bags (2-3)?				
13 Are you able to get to the clinic/hospital to collect your medication or for rehabilitation/nursing/ medical help?				
14 Are you able to use the same transport you used before the stroke?				
15 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?				
16 Are you able to get out of the house to go shopping in town or going out with friends or watch a soccer match at a stadium?				

Domain 2: SOCIAL INTERACTIONS AND RELATIONSHIP

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to work in your garden or fields?				
2 Are you able to attend social events in your community such as funerals, parties or weddings?				
3 Are you able to attend burial society, social club meetings and other structures meeting or meetings called by the chief/councilor in your community?				
4 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregates,?				
5 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?				
6 Are you able to do a physical activity such as playing any sport?				
7 How satisfied are you with your interaction with other people?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)

Domain 3: HOME/FAMILY RESPONSIBILITIES AND APPEARANCE

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?				
2 Are you able to cook and prepare meals for your family?				
3 Are you able to clean the area and utensils used for preparing meals?				
4 Are you able to wash the clothes?				
5 Are you able to hang the clothes on a washing line or are you able to dry your clothes the way you have always done?				
6 How satisfied are you with your appearance in public?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)
7 How satisfied are you with your ability to physically assist someone?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)

Domain 4: SOCIAL INTERACTIONS

1 How satisfied are you with your visiting other people and them visiting you?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)
2 How satisfied are you with help and support that you receive from your family and friends?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)
3 How satisfied are you with your ability to solve family and friend's problems	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)
4 Are your friends and family assisting you with your travelling needs?	No (0)	Yes, but rarely (1)	Yes, sometimes (2)	Yes, always (3)
5 Are you able to easily remember things told and events?	Not at all (0)		To some extent (1)	To a full extent (2)
6 Are you able to make decisions regarding your life and family issues?	Not at all (0)		To some extent (1)	To a full extent (2)

Domain 5: EXTENDED FAMILY RESPONSIBILITIES

Item	**No (0)**	**Able with major help (1)**	**Able with minor help (2)**	**Able with no help (3)**
1 Are you able to take care of your livestock (if you have) e.g. feed your dogs or herd/tend your cattle/ goats, including milking?				
2 Are you able to teach children home keeping tasks e.g. cultural/traditional cooking, and mudding with cow dung?				

Domain 6: WORK AND EDUCATION

Item	**No (0)**	**Able with major help (1)**	**Able with minor help (2)**	**Able with no help (3)**
1 Are you able to go back to work (paid or volunteer)?				
2 Are you able to attend school or training programmes (including adult education) in or out of your community?				

APPENDIX 5.10

OUTCOME MEASURE: RURAL SETTING VERSION

Domain 1: HOME AND FAMILY RESPONSIBILITIES

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?				
2 Are you able to work in your garden or fields?				
3 Are you able to collect firewood, chop and prepare fire?				
4 Are you able to cook and prepare meals for your family?				
5 Are you able to clean the area and utensils used for preparing meals?				
6 Are you able to wash the clothes?				
7 Are you able to hang the clothes on a washing line or are you able to dry your clothes the way you have always done?				
8 Are you able to collect water from the river/communal tap?				
9 Are you able to carry heavy object(s) for example shopping bags (2-3)?				
10 Are you able to use the same transport you used before the stroke?				

Domain 2: COMMUNITY AND SOCIAL RESPONSIBILITIES

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to attend social events in your community such as funerals, parties or weddings?				
2 Are you able to attend burial society, social club meetings and other structures meeting or meetings called by the chief/councilor in your community?				
3 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregants,?				
4 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?				

Domain 3: MOBILITY

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to pour water into a kettle/basin?				
2 Are you able to move around uneven/hilly areas?				
3 Are you able to move around in your home?				
4 Are you able to move around in your yard?				
5 Are you able to move around in your community?				

Domain 4: ADL AND SELF CARE

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to get up and out of bed in the morning?				
2 Are you able to wash yourself?				
3 Are you able to dress yourself?				
4 Are you able to feed yourself?				
5 Are you able to drink from a cup or glass?				
6 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?				

Domain 5: RELATIONSHIP

Item	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)
1 How satisfied are you with your interaction with other people?			
2 How satisfied are you with your appearance in public?			
3 How satisfied are you with your communication with family?			
4 How satisfied are you with your communication with people around you?			
5. How satisfied are you with your visiting other people and them visiting you?			
6 How satisfied are you with help and support that you receive from your family and friends?			
7 How satisfied are you with your ability to solve family and friend's problems			

Domain 6: WORK AND EDUCATION

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to go back to work (paid or volunteer)?				
2 Are you able to attend school or training programmes (including adult education) in or out of your community?				

APPENDIX 6.1

CHAPTER 6 APPENDICES: INFORMATION SHEET FOR PARTICIPANTS WHO TOOK PART IN THE CONSTRUCT VALIDITY IN STUDY 2 PHASE 3

Dear patient, Hello

My name is Douglas Maleka; I am a post-graduate student registered for PhD at the University of the Witwatersrand in Johannesburg, in the Faculty of Health Science, School of Therapeutic Sciences- Department of Physiotherapy. I would like to invite you to take part in the study that I am about to start.

The title of my study is “Development of outcome measure to assess community reintegration following stroke **for patients living in poor socioeconomic rural and urban areas of South Africa. The main aim of the study is: To develop and validate an outcome measure to assess community reintegration following stroke for patients living in poor socioeconomic rural and urban areas of South Africa.**

An outcome measure is a rating scale that will give an indication of how well you have settled in your community. The outcome measure will assist you, your family and your therapists to developing plans for your rehabilitation in the community to make you settle well into your community.

I will bring two questionnaires to your house/clinic/hospital and use them to ask you questions. The information from this two outcome measures will be compared to check whether the two are different. This will happen only once and will be done by one person (researcher).

Taking part is optional, and refusal to participate will not affect your treatment at the clinic in any way. If you wish to leave before the study is complete you may do so without affecting your treatment at the clinic in any way.What you say will be kept in secret by researchers in this interview but it cannot be guaranteed for other members of the group.

If you agree may you please sign the consent form below.

Thank you, Douglas Maleka

APPENDIX 6.2

CONSENT FORM FOR PARTICIPANTS WHO TOOK PART IN CONSTRUCT VALIDITY, STUDY 2 PHASE 3.

I have read and understood the contents of the information sheet. I therefore consent to participate in the study as outlined in the information sheet.

Patient and caregiver's names:

Signature:

Date:

APPENDIX 6.3

THE ORIGINAL ENGLISH VERSION OF THE SIPSO

Please answer all questions

1. Since your stroke, how much difficulty do you have dressing yourself fully?
(Circle One Number)

No difficulty at all.....	4
Slight difficulty.....	3
Some difficulty.....	2
A lot of difficulty.....	1
I cannot dress myself fully.....	0

2. Since your stroke, how much difficulty do you have moving around *all* areas of the home?
(Circle One Number)

No difficulty at all.....	4
Slight difficulty.....	3
Some difficulty.....	2
A lot of difficulty.....	1
I cannot move around all areas of the home.....	0

3. Since your stroke, how satisfied are you with your overall ability to perform daily activities *in and around the home*?
(Circle One Number)

Completely satisfied.....	4
Mostly satisfied.....	3
Fairly satisfied.....	2
Not very satisfied.....	1
Completely dissatisfied.....	0

4. Since your stroke, how much difficulty do you have shopping for and carrying *a few items* (1 bag of shopping or less) when at the shops?
(Circle One Number)

No difficulty at all.....	4
Slight difficulty.....	3
Some difficulty.....	2
A lot of difficulty.....	1
I cannot shop for and carry a few items.....	0

5. Since your stroke, how independent are you in your ability to *move around your local neighbourhood*?
(Circle One Number)

I am completely independent.....	4
I prefer to have someone else with me.....	3
I need occasional assistance from someone.....	2
I need assistance much of the time.....	1
I am completely dependent on others.....	0

6. Since your stroke, how often do you feel bored with your free time at home?
(Circle One Number)

I am never bored with my free time.....	4
A little of my free time.....	3
Some of my free time.....	2
Most of my free time.....	1
All of my free time.....	0

7. Since your stroke, how would you describe the amount of communication between you and your friends/associates?
(Circle One Number)

A great deal.....	4
Quite a lot.....	3
Some.....	2
A little bit.....	1
None.....	0

8. Since your stroke, how satisfied are you with the level of interests and activities you share with your friends/associates?
(Circle One Number)

Completely satisfied.....	4
Mostly satisfied.....	3
Fairly satisfied.....	2
Not very satisfied.....	1
Completely dissatisfied.....	0

9. Since your stroke, how often do *you visit* friends/others?
(Circle One Number)

Most days.....	4
At least once a week.....	3
At least once a fortnight.....	2
Once a month or less.....	1
Never.....	0

10. Since your stroke, how do you feel about your appearance when out in public?
(Circle One Number)

Perfectly happy.....	4
Slightly self-conscious.....	3
Fairly self-conscious.....	2
Very self-conscious.....	1
I try to avoid going out in public.....	0

Thank you for completing this questionnaire.

APPENDIX 6.4

AN EXAMPLE OF THE XITSONGA TRANSLATED VERSION OF THE SIPSO

Mi komberiwa ku hlamula swivutiso hinkwaswo

1. Hi mpfhuka mi oma rihlanguti, xana swi mi tikela ku fika kwihi ku tiambexa hi nwexe (Mi tsondzela nomboro yinwe hi xirhendzevutana)

   A swi ndzi tikeli na swintsongo..... 4
   Swa tikanyana..... 3
   Swa tika swinene..... 2
   Swi tika ku tlula mpimo..... 1
   A ndzi swi koti ku tiambexa..... 0

2. Hi mpfhuka mi oma rihlanguti, xana swi mi tikela ku fika kwihi ku famba-famba etindzhawini hinkwato kwala kaya (Mi tsondzela nomboro yinwe hi xirhendzevutana)

   A swi ndzi tikeli na swintsongo..... 4
   Swa tikanyana..... 3
   Swa tika swinene..... 2
   Swi tika ku tlula mpimo..... 1
   A ndzi swi koti ku tiambexa..... 0

3. Hi mpfhuka mi oma rihlanguti, xana mi enetaka ku fika kwihi hi ku kota ku endla mintirho ya siku ya kwala kaya (Mi tsondzela nomboro yinwe hi xirhendzevutana)

   Ndza enetaka hi ku hetiseka..... 4
   Ndza eneteka swinene..... 3
   Ndza enetekanyana..... 2
   Ndza eneteka sweswo..... 1
   A ndzi eneteki na ka ntsongo..... 0

4. Hi mpfhuka mi oma rihlanguti, xana swi mi tikela ku fika kwihi ku ya emavhengelelni na ku rhwala leswi mi xaveke (Mi tsondzela nomboro yinwe hi xirhendzevutana)

   A swi ndzi tikeli na swintsongo..... 4
   Swa tikanyana..... 3
   Swa tika swinene..... 2
   Swi tika ku tlula mpimo..... 1
   A ndzi swi koti ku ya na ku rhwala..... 0

5. Hi mpfhuka mi oma rihlanguti, xana mi kota ku tilawula ku fika kwihi loko swi ta eka ku famba-famba kwala mugangeni

   Ndza tilawula hi ndzexe..... 4
   Ndzi tsakela ku va na munhu ekusuhi..... 3
   Ndzi lava ku pfuniwa hi munhu minkarhi yinwana... 2
   Ndzi lava ku pfuniwa minkarhi hinkwayo..... 1
   A ndzi tilawuli..... 0

6. Hi mpfhuka mi oma rihlanguti, mi na xivundza ku fika kwihi hi nkarhi lowu mi mi nga endliki nchumu (Mi tsondzela nomboro yinwe hi xirhendzevutana)

   A ndzi na xivundza..... 4
   Ndzi na xivundzanyana..... 3
   Nkarhi wunwana ndzi na xivundza..... 2
   Nkarhi wo tala..... 1
   Nkarhi hinkwawo..... 0

7. Hi mpfhuka mi oma rihlanguti, xana mi bula ku fika kwihi exikarhi ka nwina na vanghana/maxaka (Mi tsondzela nomboro yinwe hi xirhendzevutana)

   Ngopfu..... 4
   Minkarhi yo tala..... 3
   Nkarhi wunwana..... 2
   Swintsongo..... 1
   Na swintsongo..... 0

8. Hi mpfhuka mi oma rihlanguti,xana mi eneteka ku fika kwihi eka swilo swo ti tsakisa leswi mi swi endleka na vanghana va nwina/vanhu lava mi tikumaka mi ri na vona

Ndza enetaka hi ku hetiseka..... 4
Ndza eneteka swinene..... 3
Ndza enetekanyana..... 2
Ndza eneteka sweswo..... 1
A ndzi eneteki na ka ntsongo..... 0

9. Hi mpfhuka mi oma rihlanguti, mi vhakela vanghana va nwina kumbe vanhu njhe ka ngani (Mi tsondzela nomboro yinwe hi xirhendzevutana)

Masiku yo tala..... 4
Kanwe hi vhiki..... 3
Kanwe endzhaku ka mavhiki mabirhi..... 2
Kanwe hi nhweti..... 1
Na ka ntsongo..... 0

10. Hi mpfhuka mi oma rihlanguti, xana mi titwa njhani hi leswi mi langutekisaka xiswona evanhwini (Mi tsondzela nomboro yinwe hi xirhendzevutana)

Ndza tsaka hi ku hetiseka..... 4
Ndza tichava..... 3
Ndza tichavanyana..... 2
Ndza tichava swinene..... 1
A ndzi yi laha ku teleke vanhu..... 0

Inkomo, na khensa

APPENDIX 6.5

THE ENGLISH VERSION OF THE MSCRIM RURAL SETTING VERSION

Domain 1: HOME AND FAMILY RESPONSIBILITIES

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?				
2 Are you able to work in your garden or fields?				
3 Are you able to collect firewood, chop and prepare fire?				
4 Are you able to cook and prepare meals for your family?				
5 Are you able to clean the area and utensils used for preparing meals?				
6 Are you able to wash the clothes?				
7 Are you able to hang the clothes on a washing line or are you able to dry your clothes the way you have always done?				
8 Are you able to collect water from the river/communal tap?				
9 Are you able to carry heavy object(s) for example shopping bags (2-3)?				
10 Are you able to use the same transport you used before the stroke?				

Domain 2: COMMUNITY AND SOCIAL RESPONSIBILITIES

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to attend social events in your community such as funerals, parties or weddings?				
2 Are you able to attend burial society, social club meetings and other structures meeting or meetings called by the chief/councilor in your community?				
3 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregants,?				
4 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?				

Domain 3: INDEPENDENCE (MOBILITY)

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to pour water into a kettle/basin?				
2 Are you able to move around uneven/hilly areas?				
3 Are you able to move around in your home?				
4 Are you able to move around in your yard?				
5 Are you able to move around in your community?				

Domain 4: ADL AND SELF CARE

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to get up and out of bed in the morning?				
2 Are you able to wash yourself?				
3 Are you able to dress yourself?				
4 Are you able to feed yourself?				
5 Are you able to drink from a cup or glass?				
6 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?				

Domain 5: RELATIONSHIP

Item	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)
1 How satisfied are you with your interaction with other people?			
2 How satisfied are you with your appearance in the public?			
3 How satisfied are you with your communication with family?			
4 How satisfied are you with your communication with people around you?			
5 How satisfied are you with your visitors?			
6 How satisfied are you with help and support that you receive from your family and friends?			
7 How satisfied are you with your ability to solve family and friend's problems			

Domain 6: WORK AND EDUCATION

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to go back to work (paid or volunteer)?				
2 Are you able to attend school or training programmes (including adult education) in or out of your community?				

APPENDIX 6.6

THE ENGLISH VERSION OF THE MSCRIM URBAN SETTING VERSION

Domain 1: ADL AND SELF CARE

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to get up and out of bed in the morning?				
2 Are you able to pour water into a kettle/basin?				
3 Are you able to wash yourself?				
4 Are you able to dress yourself?				
5 Are you able to feed yourself?				
6 Are you able to drink from a cup or glass?				
7 Are you able to move around uneven/hilly areas?				
8 Are you able to move around in your home?				
9 Are you able to move around in your yard?				
10 Are you able to move around in your community?				
11 Are you able to collect water from the river/communal tap?				
12 Are you able to carry heavy object(s) for example shopping bags (2-3)?				
13 Are you able to get to the clinic/hospital to collect your medication or for rehabilitation/nursing/ medical help?				
14 Are you able to use the same transport you used before the stroke?				
15 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?				
16 Are you able to get out of the house to go shopping in town or going out with friends or watch a soccer match at a stadium?				

Domain 2: SOCIAL INTERACTIONS AND RELATIONSHIP

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to work in your garden or fields?				
2 Are you able to attend social events in your community such as funerals, parties or weddings?				
3 Are you able to attend burial society, social club meetings and other structures meeting or meetings called by the chief/councilor in your community?				
4 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregants,?				
5 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?				
6 Are you able to do a physical activity such as playing any sport?				
7 How satisfied are you with your interaction with other people?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)

Domain 3: HOME/FAMILY RESPONSIBILITIES AND APPEARANCE

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?				
2 Are you able to cook and prepare meals for your family?				
3 Are you able to clean the area and utensils used for preparing meals?				
4 Are you able to wash the clothes?				
5 Are you able to hang the clothes on a washing line or are you able to dry your clothes the way you have always done?				
6 How satisfied are you with your appearance in the public?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)
7 How satisfied are you with your ability to physically assist someone?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)

Domain 4: SOCIAL INTERACTIONS

1 How satisfied are you with your visiting other people and them visiting you?	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)	
2 How satisfied are you with help and support that you receive from your family and friends?	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)	
3 How satisfied are you with your ability to solve family and friend's problems	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)	
4 Are your friends and family assisting you with your travelling needs?	No (0)	Yes, but rarely (1)	Yes, sometimes (2)	Yes, always (3)
5 Are you able to remember things told and events easily?	Not at all (0)	To some extent (1)	To a full extent (2)	
6 Are you able to make decisions regarding your life and family issues?	Not at all (0)	To some extent (1)	To a full extent (2)	

Domain 5: EXTENDED FAMILY RESPONSIBILITIES

Item	**No (0)**	**Able with major help (1)**	**Able with minor help (2)**	**Able with no help (3)**
1 Are you able to take care of your livestock (if you have) e.g. feed your dogs or herd/tend your cattle/ goats, including milking?				
2 Are you able to teach children home keeping tasks e.g. cultural/traditional cooking, and mudding with cow dung?				

Domain 6: WORK AND EDUCATION

Item	**No (0)**	**Able with major help (1)**	**Able with minor help (2)**	**Able with no help (3)**
1 Are you able to go back to work (paid or volunteer)?				
2 Are you able to attend school or training programmes (including adult education) in or out of your community?				

APPENDIX 8.1

CHAPTER 8 APPENDICES: THE DEMOGRAPHIC DATA OF PARTICIPANT (FIRST PAGE OF THE MSCRIM)

Patient's name and surname

Age

Race

Sex/gender

Years of formal education obtained

Current employment status

Current/previous occupation

Marital status

Date of stroke

Side of weakness (hemiplegic side)

Name of the interviewer

Date of the interview/assessment

Who was interviewed/assessed (patient and/or caregiver)

Location of the interview/assessment including

Setting: rural or urban

Patient's physical address including contact details

How long the patient had been living in the community before and after stroke?

Baseline and follow up assessment scores

APPENDIX 8.2

INSTRUCTIONS TO THE ASSESSOR

Explain the purpose of administering the MSCRIM to the patient and the caregiver: to assess community reintegration following stroke in order to plan on improving or maintaining it.

Administer the MSCRIM, in case of a patient not able to communicate the caregiver must be interviewed.

Start with demographic information and state whether this is baseline or follow up assessment.
At the end of the interview, add points for each domain and calculate the total score for the patient.
Interpret and provide feedback for the patient by placing the patient's score on the scale below.

Cut off points:

- 80% and above means full reintegration
- 79%-60% moderate reintegration
- 59%-41% minimal reintegration
- 40%-0% no reintegration

Discuss the way forward regarding the patient's rehabilitation goals to improve community reintegration with the patient and caregiver. The setting of rehabilitation goals should be guided by the domain(s) and item(s) that the patient obtained by the lowest scores.

APPENDIX 8.3

INSTRUCTIONS TO THE PATIENTS

The therapist will read the items concerning your community reintegration following stroke to you (patient and/or caregiver), please respond appropriately.

At end of the interview the therapist will give, you feedback regarding your community reintegration and discuss the way forward regarding your rehabilitation.