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# The responsiveness of the activity participation outcome measure in clients with stroke in a private in patient neurorehabilitation unit

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# THE RESPONSIVENESS OF THE ACTIVITY PARTICIPATION OUTCOME MEASURE IN CLIENTS WITH STROKE IN A PRIVATE INPATIENT NEUROREHABILITATION UNIT


## Tarren ‘t Hart


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

**2021**

## Declaration

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

Signature: 

14 September 2021

## Dedication

This research is dedicated to my Dad, Trevor. A man who has always been supportive of my education and who believes in ongoing development and growth of skills in all areas of life.

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## Abstract

Most assessments for evaluating functional independence or the assistance the patient requires in activities of daily living for patients with stroke in acute care in private settings are completed by the rehabilitation team including nurses. Although the reliability and validity of these assessments have been extensively researched, their responsivity to specific occupational therapy outcomes may be affected by the reporting by all members of the rehabilitation team. Assessments related to activity participation are required to demonstrate the unique contribution of the profession of occupational therapy for a patient with stroke. One such measure is the Activity Participation Outcome Measure (APOM), developed in South Africa based on the Vona du Toit Model of Creative Ability (VdTMoCA).

The aim of this study was therefore to determine the responsiveness of the APOM for measurement of change in activity participation of clients with stroke compared to other routinely used assessments. Data on three assessments, the APOM, the South African Database for Functional Medicine (SADFM) BETA© Scale and the Functional Assessment Measure (FAM) was collected on 25 participants with stroke on admission and discharge to a private neurological inpatient rehabilitation setting.

Results indicate the correlations between scores on the assessments were high indicating good convergence and therefore confirmed the measurements of similar constructs by the APOM with the BETA© and the FAM®. The change in scores had standardized response means which indicated moderately significant change on all three measures. The BETA© and the FAM® being more responsive than the APOM although the differences were not significant. The APOM was slightly less sensitive to change in clients with stroke since the instrument considers a border view of the ability to perform daily tasks based on concepts central to occupational therapy such as performance of roles in daily life, level of interest and motivation to perform tasks rather than the level of independence based on a few specified activities and limited cognitive abilities.

The potential use of the APOM and the assessment of activity participation for clients with stroke in an inpatient rehabilitation setting was confirmed by the convergence of the scores with the functional independence assessed by the BETA© and FAM®.

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## Operational Definitions

| | |
|---|---|
| Activity | Execution of a task by an individual (Jiménez Buñuales, González Diego & Martín Moreno, 2002) e.g. hair washing. |
| Capacity | An individual's capability to accomplish a skill or task (Jiménez Buñuales, González Diego & Martín Moreno, 2002) e.g. physical ability to reach and manipulate tools to wash hair along with mental abilities. |
| External Responsiveness | The amount of change over a specified time frame in an outcome measure connects to corresponding changes in a reference measure (Husted et al., 2000). |
| Health and wellbeing | A state of complete physical, mental, and social well-being and not merely the absence of illness of disease (Fox et al., 2015). |
| Internal Responsiveness | The capability of a measure to change over a specific time frame (Husted et al., 2000). |
| Occupational Performance | The dynamic experience of a person engaged in meaningful activities within an environment (Law et al., 2009). |
| Participation | A person's involvement in a life situation (Jiménez Buñuales, González Diego & Martín Moreno, 2002) e.g. going to work. |
| Performance | What a person does in their current environment (Jiménez Buñuales, González Diego & Martín Moreno, 2002). |

## Abbreviations

| | |
|---|---|
| ADLs | Activities of Daily Living |
| APOM | Activity Participation Outcome Measure |
| AusTOMs | Australian Therapy Outcome Measures |
| BETA© | SADFM BETA© Nursing Measure |
| COPM | Canadian Occupational Performance Measure |
| FAM® | Functional Assessment Measure |
| FIM® | Functional Independent Measure |
| IADLs | Instrumental Activities of Daily Living |
| ICF | International Classification of Functioning, Disability and Health |
| LMIC | Low to middle income countries |
| MBI | Modified Barthel Index |
| PACS | Partial Anterior Circulation Stroke |
| POCS | Posterior Occlusion Stroke |
| SRM | Standardized Response Mean |
| TACS | Total Anterior Circulation Stroke |
| VdTMoCA | Vona du Toit Model of Creative Ability |

# CHAPTER 1: INTRODUCTION

## 1.1 Introduction

Stroke is increasing within the South African population and has a significant impact on a person's life. It affects their ability to participate in important life roles during their most productive years (McKenna et al., 2009; Owolabi et al., 2015). As reported in literature, significantly earlier onset of stroke during a person's productive period of life is greater in low- to middle-income countries such as South Africa (Johnson et al., 2016). McKenna (2009) demonstrated the negative effect that stroke can have on a person's components of occupation including activities of daily living (ADLs), leisure, work, resulting in changes in use of time, role participation and community reintegration and thus their activity participation. With the implementation of the International Classification of Functioning, Disability and Health (ICF) there is a shift from viewing a person with a disability in terms of their body structures and functional independence to addressing their participation and performance within their social and physical context (World Health Organization., 2001). This ICF complements the philosophical basis of occupational therapy. It further emphasizes the need to align therapeutic tools with a person's performance and activity participation as an assessment in practice (Wolf et al., 2015).

In the South African private health care sector, there is an increase in accountability for the outcomes of therapeutic interventions. Occupational therapists need to support outcomes research to demonstrate the clinical and cost effectiveness of the interventions they provide for stroke rehabilitation at an acute level. This will also enhance therapists' ability to engage in evidence-based practice (Carswell et al., 2004). Although occupational therapy focuses on clients with stroke engaging in activities they find meaningful (American Occupational Therapy Association, 2014) the remediation of skills or a bottom-up approach in which specific assessments of motor and cognitive deficits is still most commonly used. The assessment of independent function in activities and participation that support the occupation based or top-down approach in occupational therapy (Christiansen & Baum, 2005) are often multi-disciplinary and do not support the effectiveness of interventions viewed as specific to occupational therapy in this context.

In the researcher's experience the assessments used in private acute stroke rehabilitation in Gauteng include the Modified Barthel Index (MBI) (Shah, Vanclay & Cooper, 1989), the Functional Independent Measure (FIM)® (Uniform Data System for Medical Rehabilitation, 2012) and the Functional Assessment Measure (FAM)® (Uniform Data System for Medical Rehabilitation, 2012). The South African Database for Functional Medicine (SADFM) BETA© Scale was developed and validated in South Africa (Loubser, Casteleijn & Bruce, 2015) as an alternate measure to the FIM® for use by nursing and rehabilitation staff in acute and chronic care of clients with disabilities .

These assessments are all completed by the members of the rehabilitation team to show evidence of progress in rehabilitation overall. They are used to determine functional independence or the assistance the patient requires with ADLs, mobility, employment, social interaction, and community mobility amongst others. Although the reliability and validity of these assessments have been extensively researched, their responsivity to specific occupational therapy outcomes may be affected by the reporting by all members of the rehabilitation team. Klein, Barlow and Hollis (2008) highlighted the importance of the use of performance-based assessments which align clinical practice with discipline-specific principles. Assessments related to activity participation are required to demonstrate the unique contribution of the profession of occupational therapy for a patient with stroke within the rehabilitation setting. While the use of these measures contributes to the specific outcomes addressed in occupational therapy, they need to be valid for the context in which the therapist works.

A specific occupational therapy assessment, the Activity Participation Outcome Measure (APOM), was developed in South Africa based on the Vona du Toit Model of Creative Ability (VdTMoCA) to measure eight domains of activity participation central to occupational therapy practice (Casteleijn, 2014). The APOM includes domains which relate to process and interaction skills, life skills as well as habits in balanced lifestyle and role performance related to everyday functioning. The assessment also considers aspects related to motivation, affect and self-esteem, which Egan et al., (2014) has shown are significantly associated with activity participation post stroke with these components being moderated by

physical well-being and the level of impairment. The use of a comprehensive assessment such as the APOM could assist in determining the effect of occupational therapy on these specific domains of activity participation in clients with stroke. However, at present there is no evidence that an assessment such as the APOM, is responsive in measuring change in clients with stroke during acute inpatient rehabilitation, to guide intervention and discharge planning within the South African context.

## 1.2 Problem Statement

Occupational therapists are ideally positioned to determine activity participation assessments that will influence the participation in all daily activities post stroke. The current assessments used to measure performance in activities in clients with an acute stroke are based on functional independence in areas of ADLs and cognition. Current measures used in practice demonstrate the multi-disciplinary input based on observation but lack the evidence of occupational therapy specific input for change in performance (Kossi et al., 2018). The APOM is an occupational therapy-specific tool for activity participation. It measures the capacity to perform daily tasks in the various areas or components of occupation (American Occupational Therapy Association, 2014). The influence of constructs such as the performance of roles in daily life, level of interest and motivation to perform tasks and life skills, are considered and can supplement the limited evidence to support participation or performance assessments beyond self-care and instrumental activities of daily living reported in the literature (Wolf et al., 2015). However, the APOM was developed to be used with clients in the mental health field of practice. There is no evidence that this assessment will be effective for use, responsive to clinical change and provide evidence for the unique contribution of occupational therapists in the rehabilitation of clients with stroke.

## 1.3 Research question

Does the responsivity of the APOM support its use when compared to routinely used assessments in an acute stroke inpatient rehabilitation unit?

## 1.4. Purpose of the study

The purpose of this study is to determine the responsiveness to change in activity participation using the APOM compared with the responsiveness to change in functional independence measured by the BETA© and the FAM®. Functional independence assessments consider physical and cognitive influences for clients with stroke in a neurological inpatient rehabilitation setting. The convergence of scores on the APOM and the BETA© and the FAM® is also used to determine if the outcomes measured are similar to support the relevance of the use of the APOM with this population.

## 1.5 Aim of the Study

To determine the responsiveness of the APOM for measurement of change in activity participation of clients with stroke in a private neurological inpatient rehabilitation setting to other routinely used assessments.

## 1.6 Objectives of the Study

1) To describe the activity participation in domains at baseline (admission) and discharge as measured by the APOM and the functional independence as measured by the BETA© and the FAM® in clients with stroke in an inpatient rehabilitation setting
2) To evaluate the convergence of the activity participation assessed by the APOM and functional independence assessed by the BETA© and FAM® for clients with stroke in an inpatient rehabilitation setting
3) To compare responsiveness to change in activity participation with the APOM with responsiveness to change in functional independence with the BETA© and the FAM® in clients with stroke in an inpatient rehabilitation setting.
4) To determine the difference between scores at baseline and discharge and the change in scores for activity participation and functional independence and demographic factors in clients with stroke in an inpatient rehabilitation setting.

## 1.7 Hypothesis

*Null Hypothesis*

The APOM shows similar responsiveness to change in activity participation compared to change in functional independence assessed by the BETA© and FAM® for clients with stroke in an inpatient rehabilitation setting.

*Alternate Hypothesis*

The APOM shows greater responsiveness to change in activity participation compared to change in functional independence assessed by the BETA© and FAM® for clients with stroke in an inpatient rehabilitation setting.

## 1.8 Significance of the study

With activity participation as a growing area of focus in healthcare, occupational therapists are optimally positioned to target interventions in this area. Currently used assessments of activity participation in practice focus on a stroke survivor's performance in mobility and self-care activities despite using broader interventions to address social interaction, leisure participation, return to work, and engagement in community activities. Routine assessments need to be conducted to prove effectiveness of participation interventions and guide further interventions through specific goal-setting (Kessler & Egan, 2012). Routinely used activity participation assessments have been developed internationally and are administered by the multidisciplinary team. There is a need for a routinely used assessment that can be applied in the South African context to effectively demonstrate the contribution of occupational therapy in stroke rehabilitation.

# CHAPTER 2 LITERATURE REVIEW

## 2.1 Introduction

This chapter reviews current literature on the epidemiology of stroke as well as the defects in activity participation that occur post stroke and the assessments available to determine activity participation in clients with or without stroke. The psychometric properties of the assessments are also considered as well as the outcomes in terms of activity participation in clients with stroke receiving acute and post-acute rehabilitation.

A comprehensive search of online databases was conducted, namely Science Direct, EBSCOhost, Sage, PubMed and Taylor & Francis, to identify and evaluate the most used activity participation assessments in stroke rehabilitation and their relevance in the South African context.

## 2.2 Stroke epidemiology

There is a high prevalence of stroke globally and Johnson et al (2016) report that stroke is the third most common cause of disability. Stroke prevalence occurs mostly in low to middle income countries (LMIC) like South Africa with a crude incidence rate of 244 per 100,000 reported in a rural area in the country (Maredza, Bertram & Tollman, 2015). In the last few decades, stroke incidence has doubled indicating a need to address the impact of stroke within the South African population according to Feigin et al., (2016) and Hoffmann, T. McKenna, K. Cooke, D. Tooth, (2003).

Haemorrhagic strokes are associated with uncontrolled hypertension. 98% of stroke patients in Africa have hypertension (Owolabi et al., 2015). Ischaemic stroke is linked with other non-communicable diseases such as diabetes mellitus and cardiac disease (Owolabi et al., 2015).

Depending on the area of the stroke, the subtype and severity of the stroke, a person's physical and cognitive skills are affected (Kwakkel & Kollen, 2013). This impacts on their ability to perform and participate in a variety of life areas and often places the burden of care on their families. It has a large-scale effect on the person, their family and their community (Feigin et al., 2016). Persons affected by stroke have reported the extensive impact the stroke has on all spheres of life; namely

social isolation, difficulty with housework, pursuing previous leisure interests and resumption of life roles (Hoffmann et al., 2003). With a growing prevalence of stroke in younger populations in South Africa and a shift in focus in rehabilitation to participation in premorbid activities including employment, domestic activities caring for others, sport and leisure activities, involvement in spiritual and personal affairs, and community activities (Cawood, Visagie & Mji, 2016). There is a need to identify assessments and interventions which address activity participation in stroke rehabilitation programmes which relate to health and wellbeing as the ultimate goal of treatment and rehabilitation (Rhoda, 2012).

## 2.3 Activity participation post stroke

Stroke has a traumatic impact on a person's life. There are limitations to participate in personally meaningful and valued activities, especially work, family, and community activities. Mayo et al (2002) report that 9% of stroke survivors have severe disability, 15% moderate disability, 23% had mild disability while 53% of the participants in their study were functionally independent six months after discharge.

When reviewing independence of stroke patients in the Western Cape on discharge from hospital, Joseph and Rhoda (2013) reported that only 18% of stroke survivors were independent in participation of ADLs with 33% needing minimal assistance with 49% being dependent. These findings differed from those in a later study by Msengana et al (2019) in a study in Gauteng which found 27% of stroke patients needed assistance to participate in ADLs, 24% used modified methods to achieve independent participation and 49% of stroke patients were independent on discharge from hospital (Msengana et al., 2019). The differences found may have been affected by the used of different assessments with different scales of measurement and different definitions of independence for participation in ADLs.

A study in Sweden which considered independence in mobility post stroke found that while 81% of stroke survivors could walk indoors, 60% could not walk outdoors and 19% were wheelchair bound. They reported 48% did not have the required mobility to visit friends limiting participation in social activities (Thorngren, Westling & Norrving, 1990). Long term it was reported that only a third of stroke survivors were not limited in participating in important ADLs such as bathing independently

and up to 50% had stopped participating in IADLs such as meal preparation, housework and shopping. In South Africa, many challenges with mobility and environmental barriers which further restrict participation. Environmental barriers including community structures not suited with persons with limited mobility, far distances to access community resources and transportation. Challenges in activity participation were also experienced with a lack of support from family and friends, difficulty accessing assistive devices and transport as well as more barriers in the environment than those reported in developed counties. In South Africa individuals often walk to access these services and utilise transport that is often unavailable or costly (Rhoda, 2012).

Rhoda et al.(2015) found clients with stroke in Africa reported they had problems doing previously performed tasks with dependency on others in terms of self-care and IADLs which affected their routine and the balance in their lifestyle. They viewed participation in relation to the Model of Participation Post-stroke (Barclay-Goddard, Ripat & Mayo, 2012) which included stroke survivors taking on a sick role and experiencing a role change post discharge which limited participation in activities. Their lack of ability to do certain tasks as well as the role restriction and in many cases communication dysfunction resulted in social isolation. Post stroke patients could not maintain their homes or grow crops for their families and these factors as well as changes in affect, perceptual and cognitive impairments associated with the stroke had an adverse effect on participation for the client with a stroke (Cawood, Visagie & Mji, 2016).

Change in participation further exacerbated psychological conditions such as anxiety, mood changes and depression. Aspects such as motivation and self-esteem then had a further impact on performance and participation post-stroke (Law et al., 1996). Differing cognitive abilities or process skills including memory and attention were deficient in more than half of stroke survivors while deficits in executive function occurred in 40% and language deficits in 26% of these patients affecting participation in instrumental activities of daily living (IADLs) (Cahn-Weiner et al., 2007). This was confirmed by Ghaffari, Rostami & Akbarfahimi (2021) who indicated the importance of assessment and intervention for these aspects including as shown by Einerson & Terrill, (2018) the impact six months post-stroke of role

changes and social activities for the stroke survivor which also affected the health of their caregivers. Egan et al. (2014) demonstrated the reciprocal impact of participation on emotional and physical wellbeing post stroke. Hence engagement in personally meaningful activities can improve overall wellbeing and general health outcomes.

A multidimensional approach that addresses mood and affect, social interaction, leisure and use of free time with an understanding of all factors that may impact activity participation, is recommended to increase participation early post-stroke to improve overall stroke recovery (Tse et al., 2019). Tse et al. (2019) indicate the importance of addressing psychosocial dysfunction since they found a one-point increase in depressive symptoms was associated with a decrease in overall activity participation, when they matched participants for stroke severity and age. A decrease in depressive symptoms was associated with a 0.31 improvement in activity participation. Research suggests that more focus in participation is required post-stroke and understanding the stroke survivors' activity participation is important for intervention outcomes.

## 2.4 Role of occupational therapy in acute stroke rehabilitation

Occupational therapy is vital within stroke rehabilitation with a shift in the demographic of stroke prevalence to a younger population, the increase in survival rates post-stroke and the impact that stroke has on the daily lives of stroke survivors (Wolf, Baum & Connor, 2009). An occupational therapist's role in stroke rehabilitation is to address the underlying impairments or barriers for the stroke survivor to engage in meaningful occupations. This involves the use of occupations as a means and an end. Occupational therapists seek to enhance participation in the areas of personal care, work, leisure, community and family life (Wolf, Baum & Connor, 2009).

However in acute stroke care there is often little emphasis on cognitive, behavioural and emotional outcomes. The effect of physical deficits on engagement in activities are seen as more important (Arsic et al., 2015). Even with collaborative treatment, goal development with the patient and their results prioritises physical impairments since these are the impairments patients are most aware of (Ellis, Focht &

Grubaugh, 2013). Mayo et al. (2015) suggest that occupational therapists should also prioritise and focus on performance skills such as goal setting, problem solving, decision making and initiating activities which need to be considered into the chronic phase of stroke. However, understanding the stroke survivors' motivation and ability to carry out these processes needs to be considered since they may not have an adequate level of creative ability (du Toit, 2009). This involves understanding motivation and self-efficacy or belief of the stroke survivor in their own abilities including aspects such as their ability to initiate, continue and complete actions to partake in meaningful activities without assistance (Jones, Mandy & Partridge, 2009). A study by Morrison, Johnston & Walter, (2000) also reported that a perceived external locus of control was a predictor of increased distress and greater feelings of hopelessness.

Assessment and treatment focus on improved activity participation may include addressing social participation after stroke with an improved a range of outcomes based on the preferences and needs of stroke survivors facing participation challenges. Occupational therapists need to implement performance-based measures as part of their standard assessment for stroke survivors, as well as focus on developing more comprehensive assessments (Wolf, Baum & Connor, 2009).

## 2.5 Measuring outcomes post stroke

Routine measurement of participation will demonstrate treatment effectiveness in stroke rehabilitation programmes and aid in directing rehabilitation goals for participation (Kessler & Egan, 2012). Occupational therapists need to evaluate the tools used for routine assessment to establish the stroke survivor's needs. Current assessments provide insufficient information to determine the stroke survivor's ability to participate in more complex occupations.

A single measure cannot effectively capture the wide range after stroke. Different instruments are required to evaluate the outcome of this complex condition effectively. This includes consideration of the severity of physical and mental deficits. In acute care, assessment tends to include mostly physical dysfunction. Emotional, cognitive and social dysfunction which also impact the stroke survivors'

ability to participate in everyday activities often takes a secondary role in rehabilitation (Mayo et al., 2002).

The prevalence of stroke is occurring in younger, more economically active individuals who participate in more complex activities. There is a need for implementing performance-based measures to attune to the unique and complex needs of a stroke survivor (Wolf, Baum & Connor, 2009). Since occupational therapy focuses functional status related to the stroke survivor's ability to engage in the desired meaningful everyday activities to improve their health and well-being, the use of activity participation measures should be a priority when providing services post stroke. These measures support the outcome of intervention provided by addressing limitations of all sequelae of the stroke allowing the occupational therapist to take individual patient strengths and goals into account. This also supports evidence for the intervention provided and justifies medical insurance funding for continued intervention (Wolf, Baum & Connor, 2009).

Activity participation measures are based to a large extent on therapist observation of the patient when engaged in activities but also self-report forms. When patients are unable to indicate activity, significant others can provide proxy reports on their ability to perform activities (Mayo et al., 2002).

### 2.5.1 Activity Participation Measures

Activity participation measures include assessments of independence in activities as well as participation or the involvement in life situations by the person or address one aspect of participation alone as defined by the ICF (World Health Organization, 2001) such as reintegration into normal living (Wood-Dauphinee et al., 1988). Although assessments which address activities and participation in clients with stroke are reported in research for the stroke population, their use is limited in the clinical situation. The focus is on intervention and outcomes in independence in self-care to a large extent (Kossi et al., 2018).

These assessments all need to demonstrate strong psychometric properties, have a short administration time and be low cost if they are to be easily used within the South African context. The measure needs to provide information for ongoing goal setting to allow the stroke patient to engage in the occupations they value and to

evaluate treatment outcomes (Kessler & Egan, 2012). The most common assessments used to determine independence in self-care or ADLs include:

#### 2.5.1.1 Modified Barthel Index

The Modified Barthel Index (MBI) is an adaptation of the 1955 tool developed by Dorothea Barthel. It was developed to monitor inpatients with neuromuscular and musculoskeletal conditions and their progress in self-care and mobility skills (Mahoney & Barthel, 1965). The instrument measures performance in 10 basic ADLs, including personal hygiene, bathing, feeding, toileting, bladder and bowel control, dressing, ambulation/wheelchair management, stair climbing and chair/bed transfer (Shah, Vanclay & Cooper, 1989). The items are measured by direct observation, weighted, and provide an indication of an overall level of dependence (maximum score of 100 indicating independence and 0–20 indicates total dependence in basic ADL). The MBI has excellent reliability, validity and internal consistency ($\alpha = 0.90$) (Shah, Vanclay & Cooper, 1989). The instrument is quick to administer and does not require any additional training to use in a variety of settings. Breytenbach (2016) concluded that the MBI's content is not valid for the use in the South African stroke population. Further criticism for use of this assessment in the South African context, is that the tool does not consider environmental factors or barriers when assessing ADL performance.

#### 2.5.1.2 Functional Independence Measure (FIM)®

The FIM was developed in 1987 in the Santa Clara Valley Medical Centre to address comprehensiveness and provide uniform measurement of functional independence and disability (Uniform Data System for Medical Rehabilitation, 2012). The FIM® instrument provides clinician-reported assessment in terms of physical and cognitive disability to determine the burden of care rather than determination of independence or dependence (Granger et al., 1993; Salter et al., 2013). The FIM® is an 18-item scale with 13 motor and 5 social-cognitive items. The FIM® assesses self-care, sphincter control, locomotion, communication, social interaction and cognition through direct observation.

An item on the FIM® is scored on a 7-point Likert scale measuring the amount of assistance required to perform that item. It is used to determine the person's level of independence, use of any adaptive or assistive devices and the percentage of a

given task completed successfully (1=total assistance, 7 = total independence). The scores are calculated to represent a range from 18 (total assistance required) to 126 (complete independence in all items). The FIM® is administered by the multidisciplinary team and can be scored in 30 minutes. Administration of the FIM® requires mandatory training and certification which is available outside of South Africa (Salter et al., 2013).

Fricke and Unsworth (1997) found that the FIM® is considered the easiest tool to use and score, when compared to the MBI. Interestingly, the MBI and FIM® motor subscale have similar psychometric characteristics in inpatients with stroke (Cohen & Marino, 2000). In the same study, Cohen et al. (2000) found evidence that the FIM® had no advantage over the Barthel Index in evaluating change in ADL performance for clients with stroke. The FIM® is considered a standard measure for use in rehabilitation units. It has shown to effectively measure the level of functional independence and activity in clients with stroke, however this measure is often inaccessible to South African practitioners due to the high cost of licencing and requirement for training overseas (Uniform Data System for Medical Rehabilitation, 2012). This measure does not establish the participation level of clients within the stroke population, nor does it evaluate the psychosocial components affected by stroke.

#### 2.5.1.3 South African Database for Functional Measures BETA© Scale

Measures used in current stroke rehabilitation settings have largely been developed in Western countries. Training for these assessments is often costly and unavailable for South African practitioners. The SADFM BETA © nursing measure (BETA©) is a South African-developed tool for the measurement of functional ability of adults including those with strokes in acute and non-acute care settings. It is modified from the FIM® and can be conducted by multidisciplinary team members (Loubser, Casteleijn & Bruce, 2015). It is suitable for use in occupational therapy as it provides similar measures in relation to independence in activities and the assistance the patient requires after discharge. Training for use of the assessment is provided in South Africa (SADFM, 2017). Construct validity has been established with Rasch analysis; and internal construct validity for item and person reliability with ranges

from 0.93 to 0.76 with persons (with various neurological conditions) in an acute setting in South Africa (Loubser, Casteleijn & Bruce, 2015).

This tool reviews a person's performance in self-care, mobility and communication. However, it does not address the psychosocial aspects of well-being nor the contextual or environmental impact on performance in each of these areas. In current practice, the FAM® can be used to address these areas. There are limited measures to address the activity domains of the ICF (World Health Organization, 2001).

Assessment of activity participation which considers other categories of occupation include:

#### 2.5.1.4 Canadian Occupational Performance Measure (COPM)

The COPM is a client-centred tool used to assess the individual's perception of occupational performance in self-care, productivity and leisure. It is used to assess change in perceived performance and satisfaction with performance over time in each area (Law et al., 1996). The COPM is administered by an occupational therapist in a 5-step process within a semi-structured interview. There is a process of identifying the needs of the client, creating goals according to these needs and plan intervention during the interview (Salter et al., 2013). The length of administration depends upon the cognitive ability of the client. This tool is client-centred as the client chooses relevant, meaningful areas to direct therapy and has a positive effect on clients and their motivation in the therapy programmes.

The client may require more time and exposure to therapy before this tool can be used. Another criticism of the COPM, is the reliability and validity of information may vary between interviewers (Salter et al., 2013). Clients with limited cognition, insight and communication may not be able to participate in an interview. Training is recommended but not required to use this tool. The use of the COPM in South Africa is relevant and useful, however impaired cognition and communications deficits are common after stroke. The tool may not be an appropriate measure for all clients in the stroke rehabilitation process. This will limit its universality in an inpatient neurorehabilitation unit. Furthermore, language barriers are often encountered in the South African healthcare context (Hussey, 2012). As COPM relies on

communication and understanding during an interview (Enemark Larsen, Rasmussen & Christensen, 2018) a translator may assist but can interfere with the therapy process. As a translator may provide impose their own understanding during communication with a client which may skew the client or therapist's original intention. Construct validity has been confirmed with components of the AusTOM OT (Unsworth et al., 2004).

#### 2.5.1.5 Australian Therapy Outcome Measures for Occupational Therapy (AusTOMs-OT)

The Australian Therapy Outcome Measures (AusTOMs) is a measure developed in Australia for three disciplinary groups (Physiotherapy, Speech and Occupational Therapy) to assess clients to determine their status according to the ICF and includes impairment, activity limitations, participation restrictions and wellbeing (Unsworth et al., 2004). The AusTOMs-OT has 12 scales assessing the areas of "Learning and Applying Knowledge, Functional Walking and Mobility, Upper Limb Use, Carrying Out Daily Life Tasks and Routines, Transfers, Transport, Self-Care, Domestic Life-Home, Domestic Life-Managing Resources, Interpersonal Interactions and Relationships, Work, Employment and Education and Community Life, Recreation and Play" (Unsworth & Duncombe, 2014). It was first published in 2004 and subsequent editions in 2007 and 2014. The measure is available for free from the Aus-TOM website with no requirement for additional training, but a DVD training video can be purchased from the website.

Current translations of the tool are available in Arabic and Swedish. Administration of this tool relies on the observation and knowledge of the client's performance to complete the 0 – 5-point Likert Scale for each area. Additional discussion with the client and/or their family members may be used to assist with scoring. Moderate to high intra-rater reliability and high test-retest reliability has been established (Scott et al., 2006). Unsworth (2008) compared studies of the measure's use at various stages of stroke rehabilitation and showed that it is an effective measure for quick administration to assess a client's status across each domain. This measure encompasses more aspects of the Occupational Therapy interventions areas in line with the ICF. It has shown to be a responsive tool to evaluate clients within the stroke

rehabilitation process at admission and discharge, however not with weekly administration which is often a requirement for inpatient rehabilitation settings.

#### 2.5.1.6 Activity Participation Outcome Measure (APOM) (Casteleijn, 2010)

The Activity Participation Outcome Measure (APOM) is a South African-developed tool that was initially developed for use by occupational therapists in the mental health care setting (Casteleijn, 2010). Further studies have proven its responsiveness of use with the forensic and traumatic brain injury client populations (Brooke, 2015; Camp, Casteleijn & Thupae, 2020). It evaluates a person's performance in 8 domains: Process skills, Communication skills, Role performance, Life skills, Balanced lifestyle, Motivation, Self-esteem and Affect (Casteleijn, 2010). This measure addresses performance in the psychosocial and role aspects highlighted as deficient in current inpatient stroke rehabilitation assessments.

It aligns itself with the holistic aspects of occupational therapy but has not yet been validated for use in the stroke population. Training for the use of this tool is available in South Africa (better accessibility and reduced financial burden compared to the FIM™).

Accessibility of the tool and its ability to measure performance in life areas affected by disability make it a useful tool for application in a private neurorehabilitation unit in South Africa. It may be a valuable measure to add to the repertoire of measures currently used in practice and provide more beneficial evidence of occupational therapy specific interventions in stroke rehabilitation. However, its responsiveness for the stroke population in a rehabilitation setting needs to be determined. Content, construct and criterion validity has been established for mental health care users (Casteleijn, 2010; Camp, 2015). Inter-rater reliability and internal consistency are good with Cronbach alpha above 0.8 for all domains (Casteleijn, 2010; Camp, 2015).

#### 2.5.1.7 Functional Assessment Measure (FAM)®

The FAM® was developed in 1987 with the additional 12 items to supplement the FIM® for clients with brain injury. Each of the following items is scored on a 7-point Likert scale: Problem solving, Adjustment to limitations, Emotion, Employability,

Social interaction, Community mobility, Safety judgement, Attention, Speech intelligibility and Comprehension. The FAM® can be completed in person, on the phone, or by reviewing the patient's medical records (Wright, 2000).

The direct translation of the FAM® to the United Kingdom (UK) was not possible, therefore a group in the UK adapted the FAM® and produced the version UK FIM+FAM®. The UK FAM® was modified from the original FAM® in the 1990s (Law et al., 2009). Changes to language such as 'Personal transportation' to 'getting about in the community' and removal of words such as 'poseyed' were implemented. The focus of the assessment was changed to emphasise what the patient did, not what they would or could do and changes to some cut off scores were made. These changes resulted in significant improvement in scoring accuracy in safety awareness and notable improvement for accuracy in Adjustment to limitations and Employability as well as leisure activities (Turner-Stokes et al., 1999).

The UK FIM+FAM® is the principal assessment for the UK National Database for Specialist Rehabilitation in clients with neurological disabilities (Turner-Stokes et al., 1999). It is used in other countries in Europe and internationally including in South Africa and has been found to be reliable in several other languages (Turner-Stokes et al., 2012). The scoring is completed by the multidisciplinary team members within 10 days of admission and within the last 7 days before discharge (Nayar et al., 2016). High internal consistency has been established in various countries within the stroke population (with Cronbach's alpha of 0.948 in cognitive subscales) (Miki et al., 2016; Nayar et al., 2016). Good intra-rater reliability has been observed. The measure has proven sensitivity to changes in functional status within different stroke populations during the rehabilitation process (Nayar et al., 2016).

The MBI's content is not valid within the South African population (Breytenbach, 2016) and with the costly training for use of the FIM® and UK FIM+FAM®, the SADFM BETA © and FAM® may be more accessible to rehabilitation units in the South African context. The AusTOMs-OT is not widely known within South Africa, hence the APOM will be compared with the SADFM BETA © and FAM®.

## 2.6 Psychometric properties of Assessments

When determining the value of any assessment, the concepts of reliability, validity and sensitivity are essential for assessments (Cohen & Marino, 2000; Salter et al., 2013). Reliability refers to the reproducibility and internal consistency of the measure during administration and scoring. Validity of an assessment needs to be high to ensure that it is testing what it intends to test.

Practicality of an assessment is important in the South African setting. Factors such as feasibility of the assessment (cost, time burden to administer, etc), interpretability (meaning of the scores) and acceptability (administration by the patient, or by proxy) are important to consider when evaluating assessments in the acute rehabilitation setting. The ability of the measure to be responsive to change in the target behaviour supports the evaluation of these factors. It is an important step to ensure improvement or decline in therapy can be established and intervention efficacy can be determined (Salter et al., 2013).

### 2.6.1 Responsiveness of Assessments

An assessment's internal responsiveness to change has been described as" the degree with which different results are obtained after repeated applications of the same instrument" (de Vet et al., 2001). External responsiveness is defined when the change is compared to that measured by another assessment to confirm "when a real change in the health status has occurred" (de Vet et al., 2001).

Responsiveness to change is used to assess modification of the patient's clinical situation and needs to be established for reporting in intervention studies. There is little consensus as to how responsivity to change should be reported and retrospective evaluation is discouraged since it is difficult and subjective (Terwee et al., 2003).

Responsiveness to change is dependent on the sample of patients with which the assessment is used. Variation in scores will differ and analytical methods depend on the type of sample. Analysis should be based on the mean change in group and responsiveness is assessed using coefficients in which both the size to change and the variability is considered such as effect sizes (Middel and Van Sonderen, 2002).

The Standardized Response Mean (SRM) is suggested as suitable to analyse responsiveness as it is independent of the sample size and takes the variability to change into account (Middel and Van Sonderen, 2002). Regression analysis also allows for comparison of change to other measures for establishing external responsiveness.

## 2.7 Summary

Stroke results in limited activity participation in many occupations across the stroke survivors every day and meaningful activities. Occupational therapy has a major role in stroke rehabilitation. When providing evidence to support the inclusion of occupational therapy as an essential service for stroke survivors valid standardised measures that quantitatively show progress and change because of various intervention strategies are required.

Although current measures rely on measuring global self-care activities, mobility, cognition, and communication occupational therapists often focus on the major life area in the self-care domain even though stroke impacts on all areas of life. There are limited measures that provide quantitative information about occupational therapy intervention in these areas.

A number of activity participation measures are available and some which assess most ADLs for self-care are used interprofessionally. This is also true for other measures such as the FAM which does consider cognition and participation in activities. Tools specifically developed for occupational therapists such as the AusTOM OT and COPM have gained more traction in addressing this in the Western context. However, there is limited access for South African occupational therapists due to demands for expensive training abroad or limited measure items that are appropriate within a South African context. The APOM measure provides a more holistic assessment that quantifies a broader range of life areas that are affected by stroke. The tool has been standardised on the mental health, forensic mental health and traumatic brain injury client populations. There is a need to identify a holistic, responsive measure for use in an inpatient rehabilitation setting in South Africa that can determine the impact of Occupational Therapy intervention within the stroke populations.

# CHAPTER 3 METHODOLOGY

## 3.1 Study Type and Design

This study is a routine outcomes research study which uses routine monitoring for the implementation of standardised assessments in the daily real life clinical setting at the beginning of and throughout intervention delivery (Boswell, 2020). Outcomes research studies the normal situation without controlling variables. It detects statistical patterns and allows for reasonable comparisons between standardised measures as well as groups of patients. Each research participant becomes their own control in the study based on the change in their scores on the measures over time (Tomlin & Borgetto, 2011). The use of this research design in this study is appropriate since routine outcomes provide valuable evidence of the impact of discipline-specific intervention. The study design allows for data collection within time and resource constraints (Duncan & Murray, 2012).

## 3.2 The research setting

The study is conducted in an inpatient neuro-rehabilitation unit in a private hospital in the Johannesburg area. Clients are referred from surrounding hospitals in the northern and central areas of Johannesburg, and occasionally from across the South African borders. The clients are screened for the unit prior to transfer and selected according to diagnosis, Glasgow Coma Scale score (>6) and appropriateness for the variety of therapeutic services available at the unit (Teasdale et al., 2014). The unit does not admit persons with a Glasgow Coma Scale score of 6 or below or persons below the age of 16 years. The unit provides services of a neurologist, a physician, a dietician, psychologists, a social worker, occupational therapists, speech therapists and physiotherapists. Length of stay at the unit varies, depending on the needs and diagnosis of the client, from 2 weeks to 3 months. There is an average of 80 people with a stroke during a 12-month period year admitted to the unit.

## 3.3 Participants

### 3.3.1 Study Population

The study sample was recruited from clients admitted to a private inpatient neurorehabilitation unit in the Johannesburg area who met the inclusion criteria and consented to the study over the year of 2019-2020.

### 3.3.2 Sample Selection

| *Inclusion Criteria* | *Exclusion Criteria* |
|---|---|
| Participants who fulfilled all 4 criteria:<br>● Diagnosed with any subtype of stroke or reoccurrence of a stroke<br>● With or without comorbidities<br>● Admitted to the research site<br>● 18 years or older (as per assessment criteria) | • Clients who were deemed medically unstable after admission or were transferred to the intensive care unit were excluded from the study<br>• Once deemed medically fit, or transferred back to the rehabilitation unit to be included in the study |

### 3.3.3 Study Sample

All-inclusive total population purposeful sampling was used as any client that sustained a stroke and was admitted to the inpatient neurorehabilitation unit during the period of study was approached to participate for this study. It is a technique to include the full spectrum of the stroke population treated at the inpatient neurorehabilitation unit (Curry, Nembhard & Bradley, 2009). Any clients deemed medically unstable are excluded until deemed fit to engage in the neurorehabilitation unit programme again.

### 3.3.4 Sample Size

Using the Raosoft sample size calculator (Raosoft Inc., 2004) with a confidence level of 95% and an error margin of 10% (Omair, 2014) the calculated sample size is 28 participants. This is based on the population size available at the research setting of 40 clients that were admitted as per the inclusion criteria in the six month

period which is the time that will be allocated to data collection. 25 participants' data is used for the final study.

## 3.4 Instrumentation and Assessments

### 3.4.1 Demographic questionnaire

A demographic questionnaire (Appendix A) designed by the researcher is used to gather demographic information of each participant. It included age of participant, gender, stroke subtype and length of stay in hospital.

### 3.4.2 Activity Participation Outcome Measure (APOM)

The Activity Participation Outcome Measure (APOM) (Appendix B) is an ordinal scale. It consists of 8 domains with 53 items: 8 process skills items, 10 communication skills items, 13 life skill items, 4 role performance items, 3 balance lifestyle items, 5 motivation items, 7 self-esteem items and 3 affect items. Interpretation of the APOM scores are as follows: - scores of 1 to 3 presents the level of Tone, 4 to 6 the level of Self-differentiation, 7 to 9 level of Self-presentation, 10 to 12 level of Passive Participation, 13 to 15 level of Imitative Participation and 16 to18 level of Active Participation (Casteleijn, 2014). Within each level there are three phases which indicate where the patient is in the level and indicate the assistance needed initially from the therapist in the therapist directed phase. This phase is followed by the patient directed phase where the patient initiates action and finally the transition phase where the patients demonstrate some behaviours expected in the next phase.

Scoring of the measure is completed after observing a participant in an activity using the 18-point category scale based on the levels of Action of Creative Ability. The measure was initially used during admission and at discharge to determine change. For the purposes of this study, it was conducted on a weekly basis by the researcher.

The APOM has been validated in persons with mental illness such as: schizophrenia, intellectual impairment, mood and personality disorders, and psychosis due to substance abuse. It is shown to have good internal consistency (Cronbach alpha above 0.8) and good inter-rater reliability (Casteleijn, 2014; Camp,

2015) probably because all raters require training. Content, construct, and criterion validity has been established for the South African population (Casteleijn, 2010).

### 3.4.3 Functional Assessment Measure (FAM) ®

The Functional Assessment Measure (FAM) ® (Appendix C) is an ordinal scale that assesses 12 items: 3 motor items e.g., swallowing, car transfers, community mobility; 1 speech and language item; 3 psychological items e.g., adjustment to limitations and emotional status and 3 cognitive items e.g., orientation, memory and problem solving. It uses a 7-point Likert scale with;

- 7 indicating complete independence (performed in a timely and safe manner)
- 6 modified independence (e.g., using a device or extended time)
- 5 requires supervision
- 4 requires minimal assistance with 25% of activity
- 3 requires moderate assistance with half the activity (50% pf the task)
- 2 requires maximal assistance with 75% of the activity
- 1 where the patient requires total assistance (Uniform Data System for Medical Rehabilitation, 2012)

Scoring of each item was based on the participant's performance in the unit. The FAM ® was completed on a weekly basis by the multidisciplinary team.

### 3.4.4 South African Database for Functional Measures BETA © Scale

The South African Database for Functional Measures BETA © Scale (Appendix D) is a 7-point ordinal scale. It assesses 18 items: 13 motor e.g. walking, bath/shower transfers, dressing and grooming; and 4 cognitive e.g. memory, concentration, and orientation. It has been measured using a wide variety of conditions such as stroke, chronic illnesses, and geriatric conditions (SADFM, 2017).

Raters require additional training to use the measure. It has shown good inter-rater reliability with a Rasch reliability range from -0.95 to -1.00 per item. Internal construct and criterion validity have been determined with the South African population. It uses a 7-point Likert scale to score each item depending on the level of dependence/independence required A score of 1-2 indicates total assistance, while a score of 3 indicates that supervision is required for <50% of the task, a score

of 4 indicates moderate assistance – needs set up and intermittent supervision, while a score of 5-6 indicates modified independence with no supervision but set up, cueing, assistive devices or extra time and a score of 7 reflects independent participation (SADFM, 2017).

The BETA © was completed on a weekly basis by the multidisciplinary team members. Scoring of the measure was based on the performance of the research participant in the unit.

## 3.5 Research Procedure

Once ethical clearance and permission for the study was obtained the participants were recruited. Research participants were approached for recruitment included any client admitted to the acute inpatient rehabilitation unit with a diagnosis of a subtype of stroke that met the inclusion criteria. The consent form and information sheet were provided to the client and/or their next of kin during the week or on a Monday morning following admission after 12pm on a Friday. The researcher explained the information sheet and consent form to them or their next of kin. Once the signed consent form was provided, the APOM was added to the initial and weekly BETA Scale© and FAM® administration conducted on a Tuesday (or Monday, if Tuesday was a public holiday).

A multidisciplinary assessment was conducted within 24 hours of admission to the unit. Within the week, discipline-specific assessments, and BETA Scale© and FAM® scores were completed by the multidisciplinary team every Tuesday (or Monday if Tuesday is a public holiday). A written report with the BETA Scale© and FAM® scores was submitted to the funders for review for continued hospitalization at the unit.

The researcher is trained in the APOM administration and conducted the APOM assessments on the same day as the BETA Scale© and FAM® was conducted. The APOM activities varied from interview questions (if possible) and observation during structured and unstructured group and individual activities with tool and object handling. The BETA Scale© and FAM® is administered (as per unit procedures) by each treating therapist (physiotherapist, occupational therapist and speech therapist as each therapist has been trained for use in the unit).

Intervention provided at the rehabilitation unit included bi-daily treatment sessions. Interventions ranged according to the clinical needs of each client. It included: gait retraining, strength and motor control retraining, cognitive and visual-perceptual rehab, activities of daily living training including use of assistive aids. At discharge, the final BETA Scale© and FAM® was scored, and discipline-specific assessments were recorded on a discharge report.

The scoring data from the weekly BETA Scale©, FAM® and APOM score sheets (see Appendices B, C and D) were entered into an excel spreadsheet. The APOM data was entered onto the online database. The use of trained multiple raters for BETA©/FAM® scoring ensured control for rater bias and all cases were included in the study unless exclusion criteria met or consent not provided or revoked. The researcher conducted the APOM scoring and entered scores onto the spreadsheet. To ensure a control for rater bias as the researcher is involved in intervention and the study, all APOM scores were not tallied until the client was discharged from the unit. For the purposes of the analysis in this study the participants scores at baseline (admission) and discharge irrespective of length of stay in the unit are used.

## 3.6 Data Analysis

Although it is usual to use non-parametric statistics to analyse the data due to the ordinal scores obtained from the three assessments and the small sample size in this study means and standard deviations were used since responsiveness is analysed using standardised response means.

For the correlations between the test scores Spearman's non parametric correlation coefficients were used however.

Data were categorised according to the type of data for demographics which was nominal and ordinal data so descriptive frequencies were used to present these results. Details of the stroke subtest according to demographic variables is also presented.

Details of the analysis used for each objective are presented in Table 3.1.

**Table 3.1: Methods of Data Analysis for Each Study Objective**

| OBJECTIVE | DATA SOURCE | DATA TYPE | DATA ANALYSIS |
|---|---|---|---|
| 1) To describe the activity participation in domains at baseline (admission) and discharge as measured by the APOM and the functional independence as measured by the BETA© and the FAM® in clients with stroke in an inpatient rehabilitation setting | Baseline (admission) and discharge scores | Ordinal | Mean and standard deviation of scores pre and post-test. |
| 2) To evaluate the convergence of the activity participation assessed by the APOM and functional independence assessed by the BETA© and FAM® for clients with stroke in an inpatient rehabilitation setting | Domain and sub test scores for the APOM, BETA © Scale and FAM® at baseline and discharge<br>Total scores for the APOM, BETA © Scale and FAM® at baseline and discharge | Ordinal<br>Ordinal | Descriptive analysis using Spearman correlation<br>Multiple regression Analysis of scores |
| 3) To compare responsiveness to change in activity participation with the APOM with responsiveness to change in functional independence with the BETA© and the FAM® in clients with stroke in an inpatient rehabilitation setting. | Difference in domain and sub test scores for the APOM, BETA © Scale and FAM® from baseline to discharge | Ordinal | Standardized Response Mean (SRM) of the domains in both measures<br>Two tail t-test to determine difference between SRM |

| | | | |
|---|---|---|---|
| 4) To determine the difference between scores at baseline and discharge and the change in scores for activity participation and functional independence and demographic factors in clients with stroke in an inpatient rehabilitation setting. | Difference in domain and sub test scores for the APOM, BETA © Scale and FAM® from baseline to discharge and independent variables (age, gender, length of stay and subtype of stroke) | Ordinal | Mann Whitney U test for gender and Chi Squared test for other variables. When specific demographic groups had less than five participants a Fischer's exact test was used. |

## 3.6 Ethical Considerations

Ethical clearance was applied through the Human Research Ethics Committee at the University of the Witwatersrand (M 181125). (Appendix E). Data collection only commenced once written approval was received from the hospital management and private hospital group research council prior to study commencement (Appendix F). All clients with stroke or their next of kin (if the client with a stroke could not give informed consent) were provided with an information sheet explaining the study as an invitation to participate in the study (Appendix G). Participants or if their GCS was below 15, family members were asked to sign an informed consent form, which ensured autonomy and beneficence (Appendix H).

Confidentiality of the participants was ensured by coding each assessment form and the online data recorded under the code with their names omitted. All participants were assured that participation was voluntary and that they could refuse to participate or withdraw from the study at any time to ensure further autonomy. Refusal to participate and withdrawal from the study would have no consequences in terms of their treatment to adhere to the ethical principle of non-maleficence. There were no risks to the participants of the study who received intervention as usual in terms of beneficence.

The researcher and supervisors were the only people to access the raw data and all data was kept in a secured locked environment for 5 years or until published. Feedback on the study was available on request. The researcher ensured the

quality and integrity of the study by accepting the findings of the study and reporting them truthfully.

# CHAPTER 4 RESULTS

## 4.1. Introduction

This chapter details the trends from the analysis of the raw data collected during this study. This will be represented through tables and graphs. The patterns of change in activity participation as measured by the APOM, BETA© and FAM® in clients with stroke in an inpatient rehabilitation unit will be discussed. The responsiveness to change of the APOM, BETA© and FAM® will be compared. Twenty-eight participants were recruited into the study and demographic information and baseline assessments completed for them. However, three participants were discharged after the first week so follow up assessments could not be completed. Data comparing the baseline assessments and assessments at discharge are presented for the remaining 25 participants.

## 4.2. Demographics of the sample

There was equal representation in males and females with 14 participants for each gender. The highest percentage of participants fell into the age groups 51 – 60, 61 – 70 and 71 – 80-years (Table 4.1).

**Table 4.1: Demographics of sample (n=28)**

| | | n | % |
|---|---|---|---|
| Gender | Males | 14 | 50.00 |
| | Females | 14 | 50.00 |
| Age | 18-30 | 1 | 3.58 |
| | 31-40 | 3 | 10.70 |
| | 41-50 | 2 | 7.15 |
| | 51-60 | 6 | 21.43 |
| | 61-70 | 6 | 21.43 |
| | 71-80 | 6 | 21.43 |
| | 81 - 90 | 3 | 10.70 |
| | 91 - 100 | 1 | 3.58 |
| Length of stay | 1-2 weeks | 7 | 25.00 |
| | 3-4 weeks | 8 | 28.57 |
| | 5-6 weeks | 9 | 32.15 |
| | 7-9 weeks | 4 | 14.28 |

**Table 4.2: Stroke subtype according to gender and age (n=28)**

| | | Total Anterior Circulation Stroke | Partial Anterior Circulation Stroke | Posterior Occlusion Stroke | Lacunar stroke | Haemorrhagic Stroke |
|---|---|---|---|---|---|---|
| | | n(%) | | | | |
| Gender | Male | 2(7.15) | 6 (21.43) | 4(14,28) | 1(3.58) | 1(3.58) |
| | Female | 4(14.28) | 7(25.00) | 2(7.15) | | 1(3.58) |
| Age | 16-30 | 1(3.58) | | | | |
| | 31-40 | | 2(7.15) | 1(3.58) | | |
| | 41-50 | | | 2(7.15) | | |
| | 51-60 | 3(10.70) | 3(10.70) | | | |
| | 61-70 | 1(3.58) | 2(7.15) | 1(3.58) | 1(3.58) | 1(3.58) |
| | 71-80 | 1(3.58) | 3(10.70) | 1(3.58) | | 1(3.58) |
| | 81-90 | | 2(7.15) | 1(3.58) | | |
| | 91-100 | | 1(3.58) | | | |
| Total | | 6 (21.43) | 13(46.41) | 6 (21.43) | 1(3.58) | 2(7.15) |

When the stroke subtype was compared for gender and age females presented with a higher percentage of Total Anterior Circulation Stroke (TACS) and Partial Anterior Circulation Stroke (PACS) and males with Posterior Occlusion Stroke (POCS). PACS, TACS, Lacunar and Haemorrhagic stroke were more common in participants over the age of 50 years while a similar percentage of participants over and under 50 years presented with POCS.

## 4.3 The Activity Participation Outcome Measure, the South African Database for Functional Measures BETA © Scale and the Functional Assessment Measure®

### 4.3.1 Change in scores from baseline at admission to discharge

Table 4.3 indicates the scores for all three assessments, the APOM, BETA© and FAM® for all domains on the assessments. (Table 4.3).

**Table 4.3: Mean scores for the Activity Participation Outcome Measure, the South African Database for Functional Measures BETA © Scale and the Functional Assessment Measure® at baseline and on discharge (n=25)**

| **APOM** | | | **BETA©** | | | **FAM®** | | |
|---|---|---|---|---|---|---|---|---|
| | Mean (SD) | | | | | | | |
| | Baseline | Discharge | **Motor** | Baseline | Discharge | | Baseline | Discharge |
| Process Skill | 9.26 (3.17) | 10.38 (3.11) | Eating | 4.12 (1.27) | 5.24 (1.30) | Swallowing | 5.60 (1.85) | 6.32 (1.22) |
| Communication | 10.64 (3.66) | 11.18 (3.54) | Grooming | 3.80 (1.41) | 4.80 (1.55) | Car Transfers | 2.80 (1.83) | 4.08 (1.91) |
| Life skills | 7.92 (3.39) | 8.68 (3.33) | Bathing | 3.28 (1.46) | 4.36 (1.78) | Community Mobility | 2.08 (1.71) | 3.36 (1.91) |
| Role Performance | 9.22 (3.87) | 9.72 (3.74) | Dressing – upper body | 3.72 (1.43) | 4.72 (1.54) | Reading | 4.28 (2.03) | 4.52 (2.06) |
| Balanced Lifestyle | 8.96 (3.58) | 9.80 (3.65) | Dressing – Lower body | 3.28 (1.51) | 4.28 (1.59) | Writing | 3.80 (1.85) | 4.24 (1.49) |
| Motivation | 9.48 (3.48) | 10.12 (3.62) | Toileting | 3.40 (1.55) | 4.68 (1.70) | Speech Intelligibility | 4.88 (1.81) | 5.36 (1.75) |
| Self esteem | 9.88 (3.49) | 10.40 (3.57) | Bladder | 3.72 (1.95) | 5.08 (2.02) | Emotional Status | 2.84 (1.21) | 3.72 (1.49) |
| Affect | 9.48 (3.38) | 10.24 (3.74) | Bowel | 3.72 (1.88) | 5.08 (2.02) | Adjustment to limitations | 2.80 (1.22) | 3.76 (1.48) |
| **APOM Total** | 74.84 (27.18) | 80.52 (27.38) | Transfer Bed/Chair | 3.68 (1.57) | 4.72 (1.59) | Use of leisure time | 3.12 (1.20) | 4.44 (1.71) |
| | | | Transfer Toilet | 3.28 (1.70) | 4.44 (1.83) | Orientation | 4.44 (1.80) | 4.72 (1.51) |
| | | | Transfer Bath/ Shower | 3.12 (1.62) | 4.04 (1.88) | Concentra-tion | 3.76 (1.27) | 4.72 (1.51) |
| | | | Walker/ Wheel chair | 2.92 (1.85) | 3.52 (2.08) | Safety Awareness | 2.88 (1.56) | 3.88 (1.54) |
| | | | Stairs | 2.44 (1.96) | 5.08 (1.80) | | | |
| | | | **Cognitive** | | | | | |
| | | | Compre-hension | 4.80 (1.58) | 4.92 (1.89) | | | |
| | | | Expression | 4.60 (1.83) | 4.92 (1.89) | | | |
| | | | Social Interaction | 4.28 (1.84) | 4.76 (1.93) | | | |
| | | | Problem Solving | 3.44 (1.36) | 4.04 (1.57) | | | |
| | | | Memory | 3.56 (1.39) | 4.08 (1.55) | | | |
| **APOM Total** | 74.84 (27.18) | 80.52 (27.38) | **BETA© Motor Total** | 44.58 (19.37) | 60.04 (20.66) | **FAM® Total** | 43.28 (14.70) | 53.60 (17.28) |
| | | | **BETA© Cognitive Total** | 20.68 (7.40) | 22.56 (8.27) | | | |
| | | | **Total** | 65.16 (24.08) | 82.60 (27.59) | | | |

The results indicate an improvement in mean scores for all domains for the stroke survivors between baseline on admission and discharge. The participants' level of creative ability on the APOM mean scores improved one level from Self Presentation (7 to 9) to Passive Participation (10 to 12). The mean scores on the BETA© indicated improvement from supervision is required for <50% of the task (score 3) to only moderate assistance required with set up and intermittent supervision (score 4). The mean scores on the FAM® varied but indicated improvement from maximal assistance to moderate assistance (score 2-3) or improvement from moderate assistance to minimal assistance (score 3-4) or supervision required (score 5).

## 4.4 The convergence activity participation and functional independence

The convergence of the APOM and the measurement of activity participation with clients with stroke was determined by correlating the scores of each domain and the total score of the APOM with the scores of the total BETA©, BETA© motor, BETA© cognitive and the total FAM® (Table 4.4).

The APOM domains showed a strong or excellent correlation, with the total score BETA© and FAM® at baseline and discharge apart from the BETA© motor scores at baseline. The excellent correlation above 0.80 for BETA© cognitive scores and FAM® at baseline indicates the relationship between the measure of activity participation and functional independence.

At discharge with improvement in BETA© Motor Total scores to independence with moderate assistance required with set up and intermittent supervision, the correlations between the APOM domains and the total score BETA© and FAM® as well as BETA© motor and cognitive scores all had excellent correlations above 0.08.

**Table 4.4 Correlations between the domains of the Activity Participation Outcome Measure, the scores on the South African Database for Functional Measures BETA © Scale and the Functional Assessment Measure® at admission and baseline (n=25)**

| **Baseline at admission** | **BETA© Total** | **BETA© Motor Total** | **BETA© Cognitive Total** | **FAM® Total** |
|---|---|---|---|---|
| | | rho | | |
| Process Skill | **0.77** | 0.62 | **0.89** | **0.80** |
| Communication | **0.74** | 0.57 | **0.90** | **0.84** |
| Life skills | **0.82** | 0.70 | **0.85** | **0.84** |
| Role Performance | **0.75** | 0.63 | **0.80** | **0.76** |
| Balanced Lifestyle | **0.78** | 0.66 | **0.83** | **0.82** |
| Motivation | **0.77** | 0.63 | **0.85** | **0.81** |
| Self esteem | **0.79** | 0.65 | **0.87** | **0.84** |
| Affect | **0.74** | 0.60 | **0.85** | **0.80** |
| APOM Total | **0.79** | 0.65 | **0.88** | **0.84** |
| **Discharge** | **BETA© Total** | **BETA© Motor Total** | **BETA© Cognitive Total** | **FAM® Total** |
| Process Skills | **0.89** | **0.83** | **0.90** | **0.88** |
| Communication | **0.90** | **0.84** | **0.93** | **0.90** |
| Life skills | **0.90** | **0.87** | **0.83** | **0.87** |
| Role Performance | **0.88** | **0.84** | **0.84** | **0.86** |
| Balanced Lifestyle | **0.90** | **0.86** | **0.84** | **0.88** |
| Motivation | **0.90** | **0.85** | **0.87** | **0.87** |
| Self esteem | **0.91** | **0.87** | **0.87** | **0.89** |
| Affect | **0.90** | **0.85** | **0.87** | **0.87** |
| APOM Total | **0.92** | **0.87** | **0.89** | **0.90** |

Figure 4.1 indicates the scatterplots of the scores on the three assessments as well as the BETA© motor and cognitive scores. The cognitive BETA© scores indicate the least scatter from the APOM at baseline and discharge with scatter in all scores

at discharge in relation to the APOM being less as indicated by the higher correlations at discharge in Table 4.4.

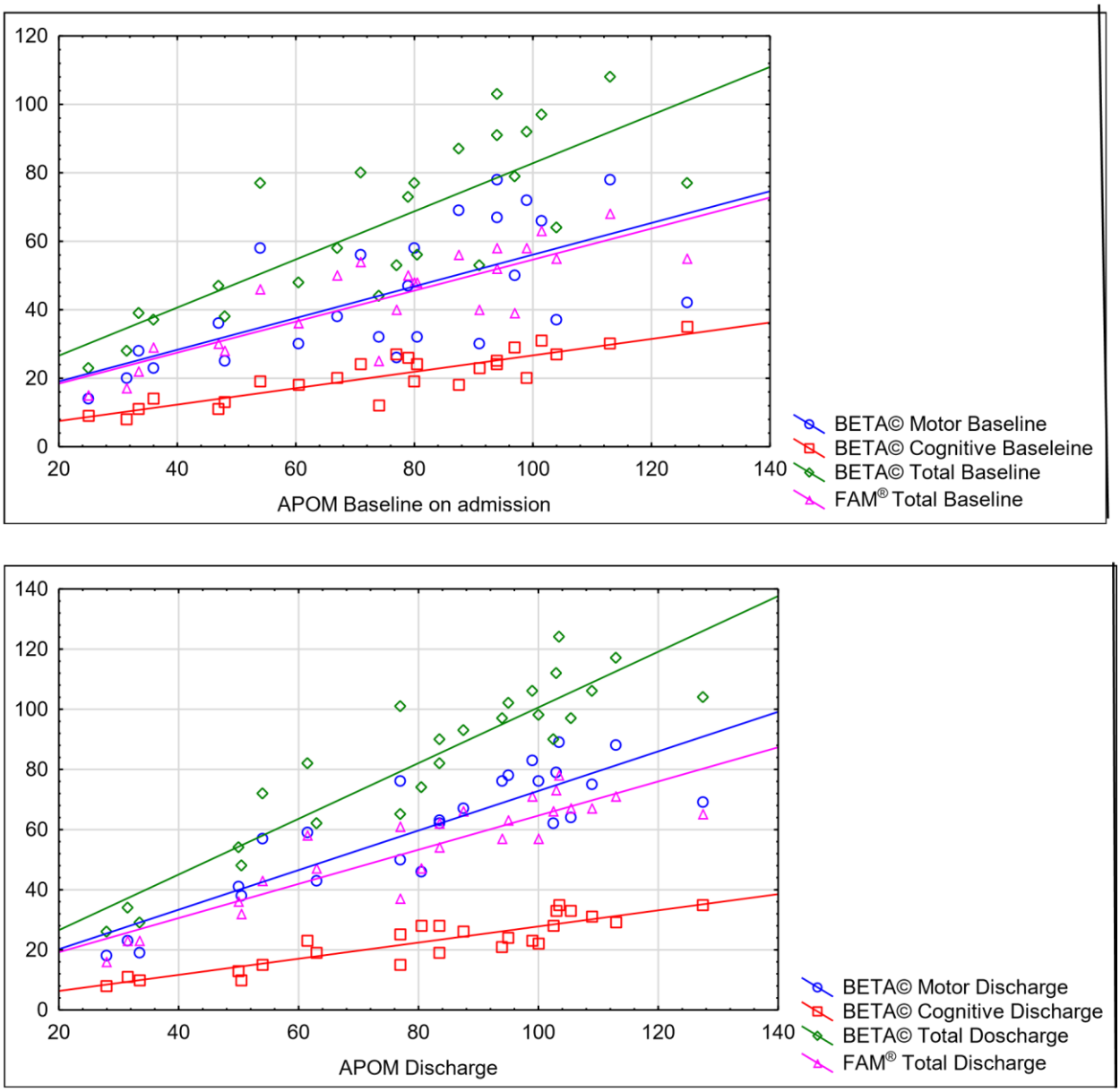


**Figure 4.1: Activity Participation Outcome Measure, the South African Database for Functional Measures BETA © Scale and the Functional Assessment Measure® at baseline and discharge for clients with stroke (n=25)**

Multiple regression analysis confirmed the relationship of the scores with slightly higher coefficient of determination indicating the percentage variance in the APOM that can be accounted for by variance in the FAM® as well as BETA© being 75% and 82% respectively (Table 4.5).

**Table 4.5 Multiple regression of the total Activity Participation Outcome Measure, the South African Database for Functional Measures BETA © Scale and the Functional Assessment Measure® at baseline and discharge (n=25)**

| **Dependent Y** | **APOM Baseline at admission** | | | **APOM Discharge** | | |
|---|---|---|---|---|---|---|
| Coefficient of determination $R^2$ | 0.78 | | | 0.85 | | |
| $R^2$-adjusted | 0.75 | | | 0.82 | | |
| Residual standard deviation | 11.87 | | | 11.49 | | |
| Independent variables | Coefficient | Std Error | p | Coefficient | Std Error | p |
| (Constant) | 6.28 | | | 4.29 | | |
| BETA© Total | 0.11 | 0.25 | 0.653 | 0.34 | 0.00 | |
| BETA© Motor | 1.90 | 0.56 | 0.002 | 0.49 | 0.00 | |
| BETA© Cognitive | 0.36 | 0.48 | 0.462 | 1.76 | 0.00 | |
| FAM® | 0.11 | 0.25 | 0.656 | -0.44 | 0.66 | 0.508 |
| Analysis of Variance | | | | | | |
| Source | DF | Sum of Squares | Mean Square | DF | Sum of Squares | Mean Square |
| Regression | 3 | 10596.18 | 3532.06 | 4 | 15353.79 | 3838.44 |
| Residual | 21 | 2960.45 | 140.97 | 20 | 2643.27 | 132.16 |
| F-ratio | 25.05 | | | 29.04 | | |
| Significance level | p<0.0001 | | | p<0.0001 | | |

## 4.5 Responsiveness to clinical change of the Activity Participation Outcome Measure, the South African Database for Functional Measures BETA© Scale and the Functional Assessment Measure®

The standardized response means (SRM) is used to determine the responsiveness of the APOM, BETA© and FAM® to clinical change or the sensitivity of the assessments in detecting difference between baseline and discharge by indicating the effect size of the change (Table 4.6).

**Table 4.6: Change in scores and standardized response means of Activity Participation Outcome Measure, the South African Database for Functional Measures BETA © Scale and the Functional Assessment Measure®**

| **APOM** | | | **BETA©** | | | **FAM®** | | |
|---|---|---|---|---|---|---|---|---|
| **Domains** | **Mean Change (SD)** | **SRM** | **Domains** | **Mean Change (SD)** | **SRM** | **Domains** | **Mean Change (SD)** | **SRM** |
| | | | **Motor** | | | | | |
| Process skills | 1.12 (1.19) | 0.93 | Eating | 1.12 (0.97) | 1.15 | Swallowing | 0.72 (0.63) | 0.63 |
| Communication | 0.50 (0.92) | 0.58 | Grooming | 1.00 (1.08) | 0.92 | Car transfers | 1.28 (0.08) | 0.97 |
| Life skills | 0.76 (1.05) | 0.72 | Bathing | 1.08 (1.22) | 0.88 | Community mobility | 1.28 (0.20) | 0.86 |
| Role performance | 0.50 (0.97) | 0.51 | Dressing Upper body<br>Lower body | 1.00 (1.04)<br>1.00 (1.22) | 0.96<br>0.81 | Reading | 0.24 (0.03) | 0.27 |
| Balance lifestyle | 0.84 (0.98) | 0.85 | Toileting | 1.28 (1.24) | 1.03 | Writing | 0.44 (0.09) | 0.61 |
| Motivation | 0.64 (0.99) | 0.64 | Bladder | 1.36 (1.57) | 0.86 | Speech intelligibility | 0.48 (0.05) | 0.55 |
| Self esteem | 0.52 (0.91) | 0.56 | Bowel | 1.36 (1.52) | 0.89 | Emotional status | 0.88 (0.27) | 0.90 |
| Affect | 0.76 (1.16) | 0.65 | Transfers Bed/Chair | 1.04 (0.79) | 1.06 | Adjustment to limitations | 0.96 (0.25) | 0.87 |
| | | | Transfers Toilet | 1.16 (1.14) | 1.01 | Use of leisure time | 1.32 (0.92) | 1.05 |
| | | | Transfers Bath/Shower | 0.92 (1.32) | 0.69 | Orientation | 0.28 (0.04) | 0.21 |
| | | | Walk/ wheelchair | 0.60 (1.55) | 0.38 | Concentration | 0.96 (0.23) | 0.68 |
| | | | Stairs | 2.64 (2.23) | 1.18 | Safety awareness | 1.00 (0.07) | 0.92 |
| | | | **Cognitive** | | | | | |
| | | | Comprehension | 0.12 (1.05) | 0.11 | | | |
| | | | Expression | 0.16 (0.94) | 0.16 | | | |
| | | | Social interaction | 0.48 (0.87) | 0.55 | | | |
| | | | Problem solving | 0.60 (0.95) | 0.62 | | | |
| | | | Memory | 0.52 (1.00) | 0.51 | | | |
| **Total** | 5.68 (7.15) | 0.79 | **Total Motor** | 15.46 (20.01) | 1.18 | **Total** | 10.31 (9.01) | 1.13 |
| | | | **Total Cognitive** | 1.88 (7.83) | 0.53 | | | |
| | | | **Total** | 17.44 (25.83) | 1.08 | | | |

**Trivial** ≤ 0-≤0.2 **Small** ≥0.20–<0.60 **Moderate** ≥0.60–<1.20 **Large** ≥1.20

It should be noted that although all participants were found to have positive change on the APOM and the FAM®, the change for three participants' scores on the BETA©

was negative and indicated deterioration in their activities and participation when assessed by the multidisciplinary team. The mean change for all three assessments however was statistically significant at < 0.05.

The SRM cut off points suggested by Middel and van Sonderen, 2002 were used to interpret the size effect of standard response means. The findings of this study show that most SRMs except for Communication, Role performance and Self-esteem were in the moderate category (≥0.60–<1.20) for APOM. In the APOM, the greatest change is shown in process skills followed by a balanced lifestyle. The SRM for BETA© indicated moderate clinical change except for walker/wheelchair and memory. Trivial clinical change was indicated for comprehension and expression. The BETA© showed positive changes in activity participation domains (eating to toileting). The largest change is shown in stairs and the smallest change is found in comprehension. Similar results were found for the FAM® where SRMs indicated moderate change except for reading, speech intelligibility and orientation which had higher scores at baseline. In the FAM®, the greatest change is seen in use of leisure time and the smallest change is seen in orientation.

The BETA© had the highest mean change for motor domains and the lowest for cognitive domains. The mean change for the total BETA© was higher than for the total FAM® with the total APOM having a lower mean change. Dependent t-tests indicated the difference for mean change for the APOM and BETA© and FAM®. (Table 4.7).

**Table 4.7: Mean change measured by the Activity Participation Outcome Measure and Functional Independence Measure™ and Functional Assessment Measure**

| | **APOM and Total BETA©** | **APOM and BETA© motor** | **APOM and BETA© cognitive** | **APOM and FAM®** | **BETA© and FAM®** |
|---|---|---|---|---|---|
| t-value | 1.73 | 2.87 | -2.46 | 1.04 | -1.23 |
| 95% confidence intervals of difference | -0.04896 to 0.5667 | 0.1369 to 0.8370 | -0.6135 to -0.05449 | 0.1452 to 0.4452 | -0.2903 to 0.07255 |
| p value | 0.095 | 0.008* | 0.021* | 0.304 | 0.227 |

Significance p≤ 0.05*

There was no significant difference between the responsiveness in terms of mean change in scores between the BETA© and FAM®.

There was no significant difference between the APOM based on change in the total scores for the BETA©. When the BETA© domains for motor and cognitive were considered separately these differed significantly from the mean change in the APOM with greater mean change for the BETA© motor and less change in the BETA© cognitive. The APOM and FAM®. showed similar responsiveness to change in activity participation with no significant difference was found.

The changes of activity participation as measured by the SRMs of the APOM, BETA© and FAM® are presented in Figure 4.2.

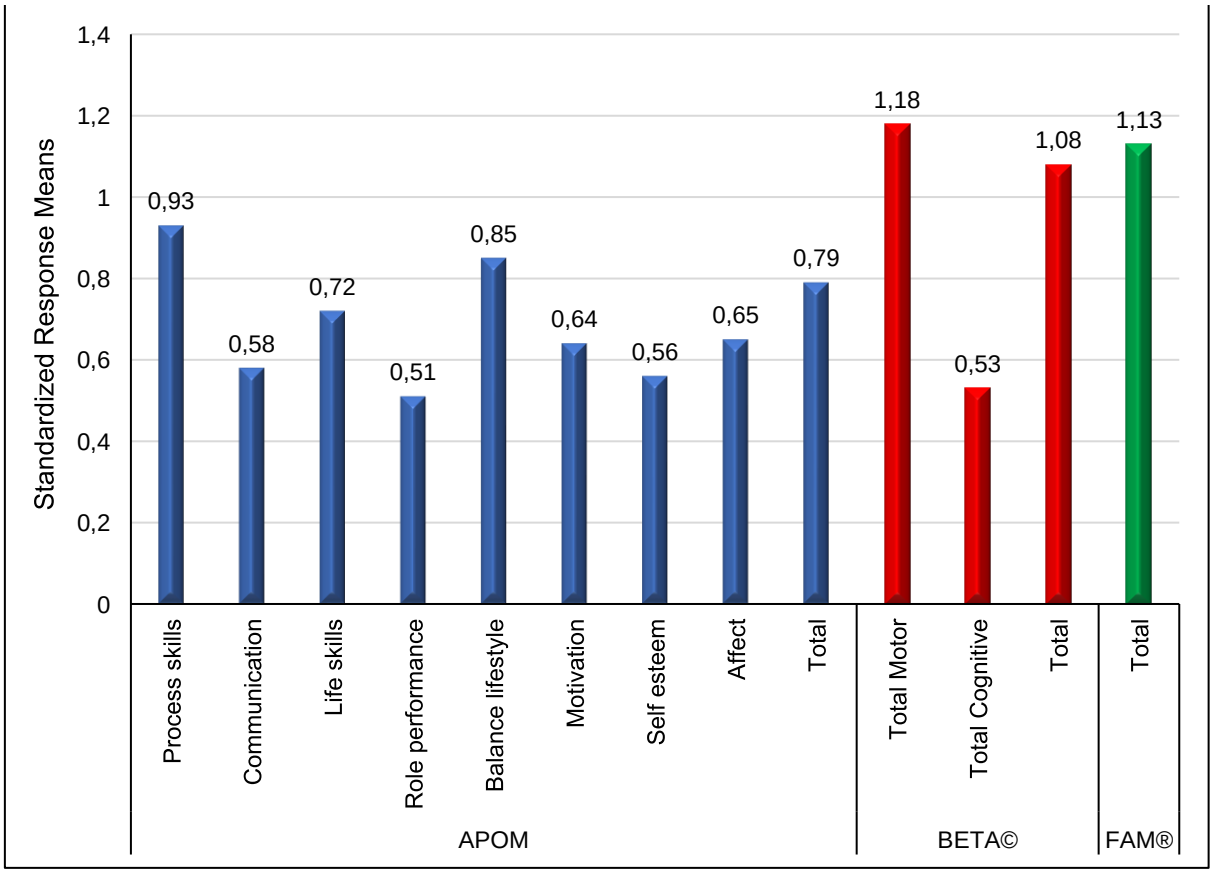


**Figure 4.2: Activity Participation Outcome Measure, the South African Database for Functional Measures BETA © Scale and the Functional Assessment Measure® standardized response means of clients with stroke (n=25)**

## 4.5 Differences between change in activity participation and functional independence and demographic factors

The differences in scores and change in scores for the APOM, BETA© and FAM® were analysed according to demographic factors to determine the responsivity to change of the outcomes measured and factors related to these clients. No significant differences were found for the demographic factors with gender and age for the APOM, BETA© and FAM®. The scores at admission ad discharge all showed a significant difference for all three assessments in assessing functional independence in stroke subtype indicating the lowest mean scores for the participants with the haemorrhagic stroke and those with TACS. The participant with the lacunar stroke had the highest scores (Table 4.8).

**Table 4.8: Differences between demographic variables and the total change on the Activity Participation Outcome Measure, the South African Database for Functional Measures BETA © Scale and the Functional Assessment Measure®**

| | | Gender | Age | Stroke Subtype | Length of Stay |
|---|---|---|---|---|---|
| | | p value | | | |
| APOM | Baseline | 0.643 | 0.391 | 0.015* | 0.189 |
| | Discharge | 0.549 | 0.186 | 0.025* | 0.112 |
| | Total Change | 0.163 | 0.147 | 0.192 | 0.164 |
| BETA © | Total Baseline | 0.567 | 0.306 | 0.022* | 0.025* |
| | Total Discharge | 0.549 | 0.186 | 0.010* | 0.081 |
| | Total Change | 0.702 | 0.696 | 0.140 | 0.139 |
| | • Motor Total Baseline | 0.462 | 0.306 | 0.069* | 0.025* |
| | • Motor Discharge | 0.414 | 0.186 | 0.008** | 0.081 |
| | • Motor Total Change | 0.549 | 0.696 | 0.151 | 0.139 |
| | • Cognitive Baseline | 0.643 | 0.696 | 0.007** | 0.543 |
| | • Cognitive Discharge | 0.743 | 0.582 | 0.008** | 0.669 |
| | • Cognitive Total Change | 0.956 | 0.414 | 0.430 | 0.147 |
| FAM® | Total Baseline | 0.414 | 0.240 | 0.011* | 0.107 |
| | Total Discharge | 0.445 | 0.193 | 0.024* | 0.267 |
| | Total Change | 0.368 | 0.460 | 0.243 | 0.044* |

Significance p≤ 0.05* p≤ 0.01**

When the length of stay was analysed, there was a significant difference for the BETA© scores at baseline or admission the BETA© motor indicating the participants with greater deficits in functional independence remained in rehabilitation for a longer period. The significant difference in the total change on the FAM® for the length of stay indicates that the greater change in functional independence on items measured by this assessment for the participants who stayed two to three weeks in the rehabilitation unit.

## 4.8. Summary

The results of the four objectives of this research were reported in this chapter. The main findings were that there is a strong to excellent correlation between the scores of APOM and the BETA© and FAM®. This could indicate a strong association of the constructs assessed by the measures and the use of the APOM with clients with stroke treated in an inpatient rehabilitation unit.

The measures showed a positive change in activity participation (as measured by the APOM) and functional independence. The SRMs in all domains of the APOM, BETA© and FAM® confirm moderate change for all three measures. The null hypothesis proposed that the APOM will show similar responsiveness to the BETA© and FAM® in demonstrating change in clients with stroke was accepted since there was no significant difference in the responsiveness of the total scores for measures. The hypothesis was rejected when comparing the responsiveness of the APOM to the BETA© motor and BETA© cognitive scores separately since the SRMs of the APOM were significantly lower than the BETA© motor and significantly higher than the BETA© cognitive. The results also indicate a significant difference in the scores at baseline and discharge on all three assessments according to stroke subtype with the larger representation of the sample with TACS and haemorrhagic subtype of stroke involving greater dysfunction in all aspects. Greater deficits in motor dependence on the BETA© resulted in a significantly longer length of stay with participants who stayed for two to three weeks having significantly greater improvement in the FAM® scores.

# CHAPTER 5 DISCUSSION

## 5.1 Introduction

This chapter discusses the trends from the results and the activity participation and independence in functional activities of daily living as measured by the APOM, BETA© and FAM® in clients with stroke in an inpatient rehabilitation unit will be discussed. The convergence of the scores on the three measures will be considered and the responsiveness to change of the APOM, BETA© and FAM® will be compared. The association between change in the activity participation and functional independence and demographic factors in clients with stroke in an inpatient rehabilitation setting will be discussed.

## 5.2 Demographic factors

Although in low to middle income countries such as South Africa, stroke is no longer a disease of the elderly due to factors such as endemic hypertension and the effects of chronic HIV infection (Maredza, Bertram & Tollman, 2015), in the current study however 78.6% of the patients were older than 50 years. The highest percentage of participants represented the age groups 51 – 60, 61 – 70 and 71 – 80-years. The literature supports this representation that stroke affects people during their most productive period in life but negates the earlier onset expected in low to middle income countries (McKenna et al., 2009; Owolabi et al., 2015; Johnson et al., 2016). The sample age range is consistent with studies of participants in inpatient rehabilitation units (Al-Jadid, Robert & Al-Jadid, 2010). The study sample is recruited from a private hospital which represents a specific population group within South Africa and the age range differs from that reported by (Msengana et al., 2019) for a South African public inpatient hospital indicating these private inpatient rehabilitation settings appear to cater to older stroke survivors. The 14.3% of participants who were over the age of 80 years reflected the increasing aged population in sub Saharan Africa presenting with stroke as elderly individuals are now living longer due to better health care (Lemogoum, Degaute & Bovet, 2005).

The gender prevalence in this study did not reflect the higher female population with stroke reported for South Africa (Bryer et al., 2010; Rhoda et al., 2014) but was

similar to other rehabilitation studies which reported a similar number of male and female participants in a later study in a similar setting (Augustyn, de Witt & Franzsen, 2020).

### 5.2.1 Medical history

The prevalence of risk profiles for stroke varies across the population groups in South Africa although, as demonstrated in the sample, there are higher incidences of ischemic stroke than haemorrhagic stroke (Bryer et al., 2010). This coincides with global trends of higher rates of ischaemic than haemorrhagic strokes (Taylor & Ntusi, 2019). Based on this literature it can be expected that due to the urban demographic of the sample used in this study, ischemic strokes would be the most common type of stroke but only 7.2% of participants in the current study presented with haemorrhagic strokes. These results are more in line with those reports for an older stroke population in high income countries and in view of the age of the participants in this study, not unexpected (O'Donnell et al., 2010).

The Partial Anterior Circulation Stroke (PACS) was the most common subtype of stroke in participants in this study (Osmani, Durrani & Ara, 2010) for nearly half the participants. Only one participant with a lacunar stroke which is associated with milder deficits compared with other subtypes and therefore patients with this type of stroke rarely require prolonged rehabilitation (Petty et al., 2000). Patients with posterior occlusion stroke are usually younger and reported to have more favourable outcomes since the lesion volume in this type of stroke does not predict outcome (Sarikaya et al., 2011).

The length of stay for the participants in the current study varies from two to nine weeks with a quarter of the participants being discharged after two weeks and 60% being discharged after three to six weeks of rehabilitation. The average length of stay in inpatient rehabilitation units is consistent with other studies (Ntsiea, 2019; Augustyn, de Witt & Franzsen, 2020).

## 5.3 The change in activity participation and change in functional independence

The first objective of the study was to describe the activity participation in domains at baseline (admission) and discharge as measured by the APOM and the functional independence as measured by the BETA© and the FAM® in clients with stroke in an inpatient rehabilitation setting

This objective determined the ability of the assessments to identify dysfunction in patients with stroke. Particularly the APOM which had not previously been researched with this population. The scores for activity participation and functional independence were expected within the acute inpatient rehabilitation setting to indicate dysfunction on admission and improvement on discharge. The mean scores for the APOM reported for all the participants from baseline on admission indicated the participants were at the Self Presentation (7 to 9) level of creative ability where they were developing behaviour and skills for norm compliance using exploration after their stroke. They were in the transitional phase for all domains except the Life skills domain which was at a therapist directed level. The skills which required therapist direction in this domain were use of transport as well as domestic and vocational skills. Participants were still exploring their abilities for participation in personal care, hygiene, grooming, personal safety, care of medication and vocational skills.

By discharge the participants scored on a Passive Participation level (10-12) in most domains on the APOM since many now used experimentation in developing new skills except for Life skills, role performance and balanced live style. The scores in these domains remained at a Self-Presentation level transitional phase due to continued problems identified at baseline as well as little improvement in role balance and competency and time use and routines and habits which were not yet well established. These aspects may have been affected by the inpatient nature of the rehabilitation which limited the participants ability to enact roles completely or develop and maintain their own routine and habits.

Participants in this study did score at a higher level on the APOM for communication which remained at Passive Participation (10 to 12) level of creative ability with a change from therapist directed to patient directed from baseline to discharge.

Scores in this domain included the patients had fewer problems with communication although some did have speech problems initially as well as the use of gestures and the body when communicating due to motor deficits related to the stroke (Rousseaux, Daveluy & Kozlowski, 2010). These findings were due to the small number of participants who had marked deficits with communication since most participants were able to adjust and use communication more effectively than overcoming the limitations caused by physical and cognitive problems. Most participants could produce intelligible speech, express basic needs and follow social norms although they still had lower scores for content, initiation of interactions and rapport (Rousseaux, Daveluy & Kozlowski, 2010).

As in other studies in South Africa using the BETA© motor component with patients with acute and subacute stroke (van Rensburg, Mudzi & Ntsiea, 2018; Msengana et al., 2019; Augustyn, de Witt & Franzsen, 2020) the levels of independence the participants presented with according to baseline scores on the BETA© indicated dysfunction with improvement at discharge. The need for moderate assistance as the activity involved motor skills were also indicated in these studies particularly for grooming, bathing and dressing. Dysfunction with mobility is also confirmed in another South African study (Joseph & Rhoda, 2013) with 33% of patients still needing minimal assistance with ADLs with 49% being dependent while Msengana et al (2019) found 49% of stroke patients were independent on discharge from hospital (Msengana et al., 2019).

The cognitive component of the BETA© used in the current study indicates moderate assistance was also required for problem solving and memory according to the cognitive skills assessment which is congruent with the study by Riepe et al. (2004) and Cawood, Visagie & Mji (2016). Setup and supervision are required for memory (Cawood, Visagie & Mji, 2016), which remains the cognitive item with the lowest score on discharge in the current study. By discharge participants no longer required assistance but required setup and supervision or had achieved modified independent in all items on the BETA© motor skills component except for mobility. This in line with other South African studies which indicates dependence in mobility remains a problem at discharge post stroke (Joseph & Rhoda, 2013; Cawood,

Visagie & Mji, 2016). A study in Sweden also reported a decrease in  in mobility post stroke (Thorngren, Westling & Norrving, 1990)

A study including the FAM® on patients with stroke as in the current study indicate dysfunction in motor, communication, and psychosocial components (Nayar et al., 2016).  Items on the FAM® indicated participants still requires minimal to moderate assistance except for swallowing and speech intelligibility. The mobility issues at baseline which was confirmed by scores on the FAM® where participants required maximal assistance with community mobility and transport (Rhoda et al., 2015) as well as use of leisure time and safety awareness. Maximal assistance for emotional status and adjustment to limitations which supports the findings of psychological distress after stroke may present a greater deficit initially than physical and cognitive issues (Doyle et al., 2004; Lund et al., 2012).

The skills measured in this assessment require further long-term rehabilitation or the practice of compensatory methods for independent to be achieved. Community mobility still requires moderate assistance and remained a problem after rehabilitation as reported by Thorngren, Westling & Norrving (1990). The findings for emotional status and adjustment to limitations where participants also presented with some moderate fall into the same category and require long term support and ongoing intervention (Lund et al., 2012).

## 5.4 Convergence of the activity participation and the change in functional independence

The second objective of the study was to evaluate the convergence of the activity participation assessed by the APOM and functional independence assessed by the BETA© and FAM® for clients with stroke in an inpatient rehabilitation setting.

Since results using the APOM have not previously been reported for a stroke population and there is limited literature on the outcomes of subacute stroke using the BETA© and the FAM®. The association between the scores at baseline and discharge were determined to assess the convergence between the constructs measured by these assessments. The excellent correlation of the APOM for BETA© cognitive scores and FAM® at baseline indicates the relationship between the measure of activity participation and functional independence related to cognitive

and other activity-based assessments. This coincides with other South African studies which show the impact of cognitive and perceptual impairments on participation (Cawood, Visagie & Mji, 2016). The APOM scores had a moderate correlation with the total BETA© motor scores at baseline when participants were admitted with the scores for functional independence in activities of daily living being more varied since some participants made little attempt to use residual motor function to carry out activities at this stage. These results are similar to those reported by Camp, (2015) for patients with traumatic brain injury (TBI) when comparing the APOM to the FIM® which measures functional independence on similar items to the BETA©.

At discharge there was a strong to excellent correlation between all APOM for BETA© and FAM® scores which highlights the convergence of domains between the three measures. It appears that participants improved and were able to adapt and adjust their skills in the presence of motor dysfunction their ability in activities of daily living scores aligned with their APOM scores on discharge. The APOM domain of Process skills, Balanced lifestyle, Self-esteem had excellent correlations with the FAM® at discharge which may reflect change in the items such as concentration and adjustment to limitations, use of leisure time, orientation and emotional status identified as part of the psychosocial factor of the FAM® on patients with stroke (Nayar et al., 2016).

All the domains on the APOM correlated excellently with the BETA© cognitive scale at baseline and discharge indicating the relationship between the assessment of functional independence related to expression, comprehension, memory, problem solving and social interaction. The excellent correlations between the Communication domain on the APOM at baseline and discharge and the FAM® is supported by the factor analysis of the FAM® which indicates a communication factor which includes speech intelligibility, writing, and reading (Nayar et al., 2016)

The regression analysis confirms high coefficients of determination between the APOM and BETA© and FAM® confirm that 75% of the variance at baseline and 82% of variance at discharge in the APOM can be accounted for by variance in the BETA© and FAM® scores. This supports the use of the APOM as an assessment

for specific use in occupational therapy to set goals and guide intervention of activity participation with patients with stroke related to their functional independence.

## 5.5 Comparison of responsiveness to change

The third objective of the study was to compare responsiveness to change of the APOM with the BETA© and the FAM® in clients with stroke in an inpatient rehabilitation setting.

To establish if the assessments were sensitive to change, the responsiveness to change in the APOM, BETA© and FAM® is related to the change in scores for each participant. The baseline scores on admission until their discharge was analyzed over the two to nine weeks of admission. All the assessments demonstrated a significantly positive mean change from baseline to discharge even though three participants did show deterioration in the BETA© motor scores as they had greater dependence on discharge due to a deterioration in their physical condition. No minimal clinically important differences (MCID) have been established for the APOM and BETA© although these have been reported on a limited basis for a similar assessment (the FIM®) but not the FAM® (Beninato et al., 2006). Therefore, the change in the current study could not be assessed for MICD.

The findings for the APOM indicate movement from one level of Creative Ability to the next during the participant's stay and all SMRs except for Communication, Role performance and Self-esteem SRMs were in moderate (≥0.60–<1.20). The SMRs in the current were not as large as the SRMs reported by Camp, Casteleijn and Thupae, (2020) on the APOM for patients with TBI. The difference may be due to the younger age, longer hospital stays of up to 17 weeks as well as the different pathology for the participants in their study. However as in the study by Camp, Casteleijn and Thupae, (2020) the lowest SRMs were found for the domains of Communication and Role performance and the highest SRM for Process skills in the current study. These results support the suggestions of that the components of Process Skills domain such as using knowledge, space and objects, and adaptation are associated with cognitive skills such as problem solving and attention (concentration) which also had change with moderate SRMs on BETA© and FAM®. respectively (Kizony & Katz, 2002).

In the current study the second greatest change on the APOM was found for the domain of Balanced lifestyle. Participation in a greater variety and number of leisure and social activities was a direct effect of rehabilitation and resulted from increased independence in activities of daily living as described by Ahn (2016) in her study. The smaller SRM for Communication may be accounted for by the higher initial scores in this domain of the APOM and that for Role performance may be due to the inability of participants to achieve role expectations and competence and while hospitalised as inpatients. The lack of improvement in this domain may also be related to participants enacting a sick role and role restriction (Rhoda et al., 2015) which is reported to affect activity participation long after discharge (Einerson & Terrill, 2018).

The BETA© showed the positive changes in all domains with large change for the functional activities of stair climbing, bowel and bladder control and toileting and moderate SRMs for all other motor scores. The results except for stair climbing were similar to those reported in other studies where mobility grooming, bathing and dressing had lower change in scores indicating participants still required some setup and supervision with these activities (Joseph & Rhoda, 2013; Msengana et al., 2019). Mobility as in other studies presented with the least change for walker/wheelchair and the large change seen for stair climbing can be accounted for by low score indicating dependence in this activity at baseline. The cognitive scores on the BETA© had trivial SRMs for comprehension and expression which had higher scores at baseline indicating only intermittent supervision was needed. The SRMs were small too, for memory and social interaction, a moderate SRM for problem solving. These are also issues, which remain problems post inpatient rehabilitation in stroke survivors, affecting their quality of life and may not as easily be improved or compensated for as motor deficits (Einerson & Terrill, 2018; Ghaffari, Rostami & Akbarfahimi, 2021).

For the FAM®, the SRMs were moderate except for the communication factors of reading, speech intelligibility which were in line with the smaller change for this domain on the APOM. The SRMs for the motor factors of car transfers and community mobility and the psychosocial factors such as emotional status and adjustment to limitations showed greater change occurred, participants remained

moderately dependent in these aspects. In the FAM®, the greatest change is seen in use of leisure time as participants were able to engage a greater range of leisure activities whilst in the rehabilitation unit with minimal assistance. As for the cognitive issues on the BETA© the lack of change allowing modified independence for motor and psychosocial factors assessed on the FAM® are reported to result in continued participation restrictions post discharge from inpatient rehabilitation (Joseph & Rhoda, 2013; Einerson & Terrill, 2018).

The responsiveness of the APOM scores in the current study were lower than those for the BETA© motor scores and the FAM® but higher than that for BETA© cognitive scores. There was no significant difference between the responsiveness in terms of mean change in scores between the APOM and total BETA© and FAM® although the responsiveness of the APOM scores differed significantly from that of the BETA© motor and cognitive mean scores. The null hypotheses that there is no difference in responsiveness between the use of the BETA© and FAM® and the APOM in demonstrating change in the acute patients with stroke in inpatient rehabilitation indicates these activities can be used successfully to indicate changes in activity participation which is the focus of occupational therapy (Casteleijn, 2014) and independent functioning focused on by other allied health professionals. However, cognisance must be taken of the significant differences found when considering motor and cognitive changes in these patients.

The significantly higher SRMs for the motor scores on the BETA© were not unexpected and confirm change according to the goals during inpatient rehabilitation in the unit for the participants', all admitted with motor deficits, which primarily focus motor function and on performance in self-care activities and mobility, even in occupational therapy (Arsic et al., 2015). The results indicate the use of the APOM alone to identify change may not be sensitive enough to identify change in activity participation reflected in change in motor performance skills in patients with stroke.

The significantly lower cognitive scores may, as indicated by Mayo et al. (2015), reflect the lack of overt goals and outcomes for these deficits in the intervention of patients with stroke resulting in less effective change during inpatient rehabilitation. Results indicate the responsivity of the APOM including the domain for Process

skills which reflect the cognitive and executive functions for activity participation is significantly more sensitive to change and should be considered for use by occupational therapists for patients with stroke since addressing this component of rehabilitation falls into the unique service offered by occupational therapy (Wolf, Baum & Connor, 2009).

## 5.6 Differences between change in the activity participation and functional independence and demographic factors

The last objective of the study was to determine the difference between scores at baseline and discharge and the change in scores for activity participation and functional independence and demographic factors in clients with stroke in an inpatient rehabilitation setting.

This objective was used to identify the ability of the assessments to differentiate between activity participation and functional limitations based on the participants demographic and medical factors. Analysis indicated that the scores on the APOM, BETA© and FAM® did not differentiate for dysfunction according to the age or gender of the participants in the current study. This was contrary to other studies which indicate older age and male patients with stroke had worse outcomes for activity participation. However, correlations reported on age differences were low (Lin et al., 2003; Osmani, Durrani & Ara, 2010) and gender differences considered domestic skills in which females may retain more independence (Kizony & Katz, 2002).

A significant difference was found for scores on all three assessments according to stroke subtype at baseline and discharge. This indicates that the stroke subtype results in different levels of dysfunction in activity participation and functional limitations measured by the APOM, BETA© total as well as motor and cognitive scores and the FAM®.

The lowest scores for all assessments were found for the participant with the haemorrhagic stroke with those with TACs, as suggested by Turhan, Atalay & Muderrisoglu (2009) and Franceschini et al. (2018), having significantly worse outcome and the participant with lacunar stroke having the best outcome. The total

change on the three assessments was not significantly different, indicating all participants irrespective of stroke subtype showed change during rehabilitation.

Participants with greater deficits in functional independence remained in rehabilitation for a longer period indicating that the positive change in both activity participation and functional independence is relevant to the length of time the participants stay in the rehabilitation unit. Factors like severity of motor deficits on admission which were significantly lower for the BETA© total as well as motor scores indicating greater motor dysfunction were related to an increased length of stay. Dysfunction measures on the APOM and FAM® did not significantly differ for length of stay, indicating admission to the unit appears to be based on physical deficits as the main factor. Only total change in FAM® scores showed a significant difference for length of time in the rehabilitation unit with those who were there for a longer period had greater improvement in the total scores. It is not clear why the change for the FAM® scores should have improved consistently but this may have been related to the larger number of psychosocial factors assessed in this assessment which improved even when participants had greater motor and cognitive deficits. The greater responsivity of the FAM® may have accounted for the significant difference which was not seen for the APOM which measured some similar outcomes in relation to activity participation.

The total change for activity participation and functional limitations measured by the APOM and BETA© were not affected by the length of stay. Those who were admitted for a longer period did not have significant improvement relative to those who were there for a shorter period since those who stayed for a shorter period had better functional independence on admission.

## 5.7 Limitations of the study

The study had a small number of participants due to the limited number of clients admitted to the rehabilitation unit monthly. This may have resulted in a greater statistical power and inflated SRMs, thus caution in interpreting the results must be used (Button et al., 2013). The setting from which the sample was taken was limited to one hospital which may have affected the variety of participants included in the study.

The researcher was the only occupational therapist who could complete the APOM, and this meant that weekly assessments had to be fitted in with other therapy which affected the time of day when participants could be observed. This may have affected their performance in activities.

The researcher held a dual role as the main researcher and a treating clinician for the participants in this study. This may have an inherent power dynamic in which the participant may not have felt comfortable to refuse participation in the study.

The study was constrained by a time limit for data collection which was time consuming since each participant was assessed once a week for the time they were admitted to the unit.

## 5.8 Summary

An assessment is a tool that can record a client's change in status over a specified period to demonstrate effectiveness of interventions, which contributes to evidence-based practice (Unsworth, 2000). The APOM, BETA© and FAM® showed the ability to determine dysfunction, as well as responsiveness to change and positive change in activity participation and functional limitations in clients with stroke in an inpatient rehabilitation unit. The excellent correlations between the BETA©, FAM® and APOM could potentially indicate that the APOM is a relevant measure for use with the stroke population. The assessments identified the difference in activity participation and functional independence for different subtypes of stroke and motor deficits related to the length of stay.

# CHAPTER 6 CONCLUSION

## 6.1 Main Findings

Traditionally, functional independence was considered as the outcome for inpatient stroke rehabilitation (Desrosiers et al., 2003). With the shift in perspective over the past few years around health and wellbeing, the ICF has acknowledged that activity participation is characterized by a variety of factors that can lead to illness and disability. Inpatient stroke rehabilitation units need to find alternative measures to effectively measure and quantify change in activity participation for third parties and funders to demonstrate efficacy of rehabilitation programmes.

In this study clinical change was found in the patients on the APOM during their inpatient rehabilitation as they adapted to their impairments as a result of stroke. The results showed the APOM is useful in determining the activity participation in the acute stages of rehabilitation. Change in goal setting based on the phases in the levels allowed for grading from therapist direction to patient initiation of tasks due to the number of increments available for scoring, was implemented over the period of admission.

The relationship between activity participation and functional independence related to cognitive and other activity-based assessments is confirmed by the excellent correlation of the baseline APOM, BETA© cognitive scores and FAM®. There was a strong to excellent correlation between all APOM for BETA© and FAM® scores at discharge which highlights the convergence of domains between the three measures. This supports the use of the APOM in assessing and setting goals in the inpatient rehabilitation setting with stroke patients.

The APOM, BETA© and FAM® showed the ability to determine functional independence, responsiveness to change and positive change in activity participation and functional independence in clients with stroke in an inpatient rehabilitation unit. The BETA© motor scale and FAM® which contains motor items, had higher responsiveness scores than the APOM which confirmed the focus on motor function as has been in suggested in the literature (Arsic et al., 2015) and that is the case in the rehabilitation unit where this study was completed.

No demographic factors were associated with differences in scores on the APOM, BETA© and FAM® but all three measures differed significantly in identifying dysfunction according to stroke subtype. The APOM unlike the BETA© motor scale did not show significant difference for length of stay since, as stated above, the focus of treatment was not activity participation but motor function. (Arsic et al., 2015)

## 6.2 Conclusion

The APOM can be used to determine change in activity participation during rehabilitation in acute stroke patients and provides evidence of dysfunction allowing graded intervention in acute stroke rehabilitation.

The convergence of the APOM scores with the other assessments supports the use of the APOM as an assessment that can be used specifically in occupational therapy to assess and provide intervention related to activity participation in patients with stroke.

The APOM is more responsive to change than the BETA© cognitive scale indicating that the assessment may be useful for assessment of effectiveness of cognitive function in patients with stroke in occupational therapy.

The APOM is sensitive as are the other assessments to stroke subtype.

## 6.3 Recommendations

### 6.3.1 Recommendations for clinical practice

The APOM is a relevant assessment for specific use in occupational therapy to set goals and guide intervention of activity participation with patients with stroke related to their functional independence.

The use of the APOM is not as sensitive as the BETA© motor scale in identifying changes in activity participation reflected in change in motor performance skills in patients with stroke although it is more sensitive to change in cognitive function. The APOM is an assessment that can be used for evidence in the unique role of the occupational therapists but other current assessments reflecting outcomes of the multidisciplinary team also need to be used during inpatient rehabilitation for stroke survivors.

The APOM provides scores for activity participation and change in clear graphic outcomes that would be easy for other members of the multidisciplinary team to understand. This provides the occupational therapist an opportunity to present evidence of change based on therapy related to activity participation.

### 6.3.2 Recommendations for further research

Further research is required with a larger study sample from various private and public inpatient and outpatient rehabilitation settings to confirm findings from this study. By introducing the APOM as a routine measurement in the rehabilitation unit data for future studies would be available.

Participants should be discharged to community services if possible or followed up at outpatient services over several months to determine further change in activity participation.

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## APPENDIX A Demographic questionnaire

PARTICIPANT CODE:_____SP - _____

AGE:_____

GENDER: MALE/FEMALE

STROKE SUBTYPE:_____

DATE OF STROKE_____

DATE OF ADMISSION:_____

DATE OF DISCHARGE:_____

-

## APPENDIX B APOM score Sheet

| Process skills | |
|---|---|
| Attention | |
| Pace | |
| Knowledge – of tools and materials | |
| Knowledge – concept formation | |
| Skills to use tools and materials | |
| Task Concept | |
| Organizing space and objects | |
| Adaptation | |
| Average | |
| **Communication / Interaction skills** | |
| Physicality – physical contact | |
| Physicality – Gazes | |
| Physicality – Gestures | |
| Physicality – Use of body | |
| Information exchange – Use of speech | |
| Information exchange – Content of conversation | |
| Information exchange – Expression of needs | |
| Information exchange – Initiate interaction | |
| Relations – Social norms | |
| Relations – Rapport | |
| Average | |

| Lifeskills | |
|---|---|
| Personal care, hygiene, grooming | |
| Personal safety | |
| Care of medication | |
| Use of transport | |
| Domestic skills | |
| Child care skills | |
| Money management, budgeting skills | |
| Assertiveness | |
| Stress management | |
| Conflict management | |
| Problem solving skills | |
| Pre-vocational skills | |
| Vocational skills | |
| Average | |
| **Role performance** | |
| Awareness of roles | |
| Role expectations | |
| Role balance | |
| Competency | |
| Average | |

| Balanced life style | |
|---|---|
| Time use and routines | |
| Habits | |
| Mix of occupations | |
| Average | |
| **Motivation** | |
| Active involvement | |
| Motives and drives | |
| Shows interest | |
| Goal directed behaviour | |
| Locus of control | |
| Average | |
| **Self-esteem** | |
| Commitment to task /situation | |
| Using feedback | |
| Self worth | |
| Attitude towards self – self-assurance | |
| Attitude towards self – satisfaction with self | |
| Awareness of qualities | |
| Social presence | |
| Average | |
| **Affect** | |
| Repertoire of emotions | |
| Control | |
| Mood | |
| Average | |

-

## APPENDIX B FAM® Score Sheet

PATIENT NAME: _____

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| DATE | | | | | | | | | | | | |
| SWALLOWING | | | | | | | | | | | | |
| CAR TRANSFERS | | | | | | | | | | | | |
| COMMUNITY MOBILITY | | | | | | | | | | | | |
| READING | | | | | | | | | | | | |
| WRITING | | | | | | | | | | | | |
| SPEECH INTELLIGIBILITY | | | | | | | | | | | | |
| EMOTIONAL STATUS | | | | | | | | | | | | |

-

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ADJUSTMENT TO LIMITATIONS | | | | | | | | | | | | |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| USE OF LEISURE TIME | | | | | | | | | | | | |
| ORIENTATION | | | | | | | | | | | | |
| CONCENTRATION | | | | | | | | | | | | |
| SAFETY AWARENESS | | | | | | | | | | | | |

Quick guide to FAM score:

1 = Patient can do nothing

2 = Patient is ‘trying’

3 = Patient can do 50% of the task but needs ‘stay with’ help

4 = Patient only needs occasional help

5 = Patient only needs supportive help eg. Supervision or setting up

6 = Patient can complete task independently but at reduced speed or with aid

7 = Patient is fully independent

## APPENDIX C - BETA Scale© Score Sheet

PATIENT NAME: _____

| | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| DATE | | | | | | | | | | | | | |
| EATING | | | | | | | | | | | | | |
| GROOMING | | | | | | | | | | | | | |
| BATHING | | | | | | | | | | | | | |
| DRESSING<br>UPPER | | | | | | | | | | | | | |
| DRESSING<br>LOWER | | | | | | | | | | | | | |
| TOILETING | | | | | | | | | | | | | |
| BLADDER | | | | | | | | | | | | | |

| | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| BOWEL | | | | | | | | | | | | | |
| BED/CHAIR/<br>WHEELCHAIR | | | | | | | | | | | | | |
| TOILET | | | | | | | | | | | | | |
| BATH/SHOWER | | | | | | | | | | | | | |
| WALK/WC | | | | | | | | | | | | | |
| STAIRS | | | | | | | | | | | | | |
| COMPREHENSION | | | | | | | | | | | | | |
| EXPRESSION | | | | | | | | | | | | | |
| SOCIAL<br>INTERACTION | | | | | | | | | | | | | |

| | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| PROBLEM SOLVING | | | | | | | | | | | | | |
| MEMORY | | | | | | | | | | | | | |

Quick guide to beta score:

1 = Patient can do nothing

2 = Patient is ‘trying’

3 = Patient can do 50% of the task but needs ‘stay with’ help

4 = Patient only needs occasional help

5 = Patient only needs supportive help eg. Supervision or setting up

6 = Patient can complete task independently but at reduced speed or with aid 7 =

Patient is fully independent

## APPENDIX D - Human Research Ethics Committee (HREC) Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Ms Tarren 't Hart

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)**

**CLEARANCE CERTIFICATE NO. M181125**

| | |
|---|---|
| **NAME: (Principal Investigator)** | Ms Tarren 't Hart |
| **DEPARTMENT:** | Occupational Therapy |
| **PROJECT TITLE:** | The responsiveness of the activity participation outcome measure in clients with stroke in a private inpatient neuro-rehabilitation unit |
| **DATE CONSIDERED:** | 30/11/2018 |
| **DECISION:** | Approved unconditionally |
| **CONDITIONS:** | |
| **SUPERVISOR:** | Prof Daleen Casteleijn and Ms Dineo Thupae |
| **APPROVED BY:** | Dr C Penny, Chairperson, HREC (Medical) |
| **DATE OF APPROVAL:** | 10/05/2019 |

**This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.**

**DECLARATION OF INVESTIGATORS**

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed November and will therefore be due in the month of November each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

11/05/2020
Date

**PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES**

## APPENDIX E - Private Hospital Group Research Committee Clearance Certificate

**RESEARCH OPERATIONS COMMITTEE FINAL APPROVAL OF RESEARCH**

Approval number: UNIV-2019-0014

Ms Tarren 't Hart

E mail: tarren.hart@gmail.com

Dear Ms 't Hart

**RE: THE RESPONSIVENESS OF THE ACTIVITY PARTICIPATION OUTCOME MEASURE IN CLIENTS WITH STROKE IN A PRIVATE INPATIENT NEURO-REHABILITATION UNIT**

The above-mentioned research was reviewed by the Research Operations Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at private Hospital, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Committee.

ii) All information regarding the Company will be treated as legally privileged and confidential.

iii) The Company's name will not be mentioned without written consent from the Committee.

iv) All legal requirements regarding patient / participant's rights and confidentiality will be complied with.

v) All data extracted may only be used in an anonymised, aggregated format and for the purposes of this specific study as specified in the proposal. The data may under no circumstances be used for any other purpose whatsoever.

vi) The research will be conducted in compliance with the GUIDELINES FOR GOOD CLINICAL PRACTICE IN HUMAN PARTICIPANTS IN SOUTH AFRICA (2016).

vii) The Company must be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from the Committee as well as a FINAL REPORT with reference to intention to publish and probable journals for publication, on completion of the study.

viii) A copy of the research report will be provided to the Committee once it is finally approved by the relevant primary party or tertiary institution, or once complete or if discontinued for any reason whatsoever prior to the expected completion date.

ix) The Company has the right to implement any recommendations from the research.

x) The Company reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects/ Company or should the researcher not comply with the conditions of approval.

xi) APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER OR COMPLETION OR DISCONTINUATION OF THE TRIAL, WHICHEVER IS THE FIRST.

We wish you success in your research.

Yours faithfully

10/4/2019

Prof Dion du Plessis
Full member: Research Operations Committee & Medical Practitioner evaluating research applications as per Management and Governance Policy

Shannon Nell
Chairperson: Research Operations Committee
**Date:** 15/4/2019

This letter has been anonymised to ensure confidentiality in the research report. The original letter is available with author of research

Anonymous

## APPENDIX F Information sheet

**THE RESPONSIVENESS OF THE ACTIVITY PARTICIPATION OUTCOME MEASURE IN CLIENTS WITH STROKE IN A PRIVATE INPATIENT NEURO-REHABILITATION UNIT**

Good day

I, Tarren ‘t Hart, am conducting a research study as part of my master’s degree in Occupational Therapy. Research is the process to learn the answer to a specific question. In this study I want to learn about the assessments that are used in South Africa. During your stay at the inpatient rehabilitation unit we use assessments to assess any changes in a client’s abilities. This study will help to look at whether other assessments are as effective as the ones currently used in the unit.

I would like to invite you to participate in the study Currently your progress in daily activities is assessed weekly using the BETA nursing measure. This information is used in your medical aid reports to motivate for continued admission at the unit.

The study aims to investigate the use of an alternate assessment called the Activity Participation Outcome Measure (APOM) and to compare the sensitivity of the results to the BETA nursing measure. The APOM will be administered on the same day as the BETA nursing measure on a weekly basis during your stay at the unit. The APOM will take 30 - 45minutes to administer.

Should you accept the invitation, please understand the participation is voluntary. If you do not wish to give permission to participate in the study or wish to withdraw your permission at any time during the study, this will not impact on your current therapy/treatment at the unit.

Efforts will be made to keep personal information confidential. Coding will be used on the data sheets to ensure your information is stored anonymously. As the researcher, I will be the only person to have access to your identifiable information. Personal information may be disclosed only if required by law. The Human Research Ethics Committee may inspect and/or copy the research records for quality assurance and data analysis.

The hospital management has given written permission for the study at the unit and the University of Witwatersrand has provided ethical clearance for the research.

Should you have any questions during the study or after your discharge from the unit, I am available to answer them. Please direct all queries to tarren.hart@gmail.com.

For any ethical concerns or questions, please contact the chairperson of the Human Research Ethics Committee at the University of Witwatersrand, Chairperson of the ethics committee Prof Penny via the administrative offices: Ms. Z Ndlovu/ Mr Rhulani Mkansi, Tel: 011 717 2700/2656/1234/1252, or email: Zanele.ndlovu@wits.ac.za; Rhulani.mkansi@wits.ac.za.

Should you wish to participate in this study please complete the acceptance slip below and return it to me.

Yours sincerely,

Tarren ‘t Hart (BSc: OT)

Occupational Therapist

## APPENDIX G Informed Consent for the Study

I, _____ agree to participate in the research project - The Responsiveness of the Activity Participation Outcome Measure in Clients with Stroke in a Private Inpatient Neuro-rehabilitation Unit.

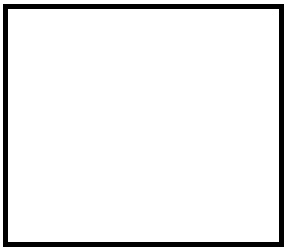
I am aware that there are no direct risks or benefits for my participation in the research study.

I understand that at any stage during the research study I may withdraw my permission for participation and that it will have no impact on my therapy at the unit.

Signature: _____ Date:

_____

Fingerprint (if unable to sign):



## APPENDIX H Informed Consent (Family Member)

I, _____ agree for my family member,_____to participate in the research project - The Responsiveness of the Activity Participation Outcome Measure in Clients with Stroke in a Private Inpatient Neuro-rehabilitation Unit.

I am aware that there are no direct risks or benefits for their participation in the research study.

I understand that at any stage during the research study I/my family member may withdraw permission for participation and that it will have no impact on their therapy at the unit.

Signature: _____

Date: _____

**APPENDIX I – Turnitin Report**

# THE RESPONSIVENESS OF THE ACTIVITY PARTICIPATION OUTCOME MEASURES IN CLIENTS WITH STROKE IN A PRIVATE INPATIENT NEURO-REHABILITATION UNIT

*by* Tarren 't Hart

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**Submission date:** 26-Mar-2021 09:14AM (UTC+0200)
**Submission ID:** 1542818308
**File name:** Chapter_1-6_T_T_Hart.docx (336.74K)
**Word count:** 16319
**Character count:** 91096

# THE RESPONSIVENESS OF THE ACTIVITY PARTICIPATION OUTCOME MEASURES IN CLIENTS WITH STROKE IN A PRIVATE INPATIENT NEURO-REHABILITATION UNIT

ORIGINALITY REPORT

| 10% | 6% | 6% | 4% |
|---|---|---|---|
| SIMILARITY INDEX | INTERNET SOURCES | PUBLICATIONS | STUDENT PAPERS |

PRIMARY SOURCES

| | | |
|---|---|---|
| 1 | Submitted to University of Witwatersrand<br>Student Paper | 2% |
| 2 | Hymeri Augustyn, Patricia de Witt, Denise Franzsen. "The effect of HIV status on post-stroke outcomes in personal activities of daily living", British Journal of Occupational Therapy, 2020<br>Publication | 1% |
| 3 | Wesley Lai, Mackenzie Buttineau, Jennifer K. Harvey, Rebecca A. Pucci et al. "Clinical and psychosocial predictors of exceeding target length of stay during inpatient stroke rehabilitation", Topics in Stroke Rehabilitation, 2017<br>Publication | 1% |
| 4 | Encyclopedia of Clinical Neuropsychology, 2011.<br>Publication | <1% |

## APPENDIX J – Plagiarism Declaration

PLAGIARISM DECLARATION

**Faculty of Health Sciences, Postgraduate Office**
Phillip V Tobias Building, 2nd Floor
Cnr York & Princess of Wales Terrace, Parktown 2193
Tel: (011) 717 2745 | Fax: (011) 717 2119
Email: Mathoto.senamela@wits.ac.za

**PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS**

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Tarren 't Hart (Student number: 0507354E) am a student registered for the degree of Occupational Therapy in the academic year two.

I hereby declare the following:

I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.

I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.

I have followed the required conventions in referencing the thoughts and ideas of others.

I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature:  Date: 14 September 2021