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THE RESPONSIVENESS AND RELEVANCE OF THE ACTIVITY PARTICIPATION OUTCOME MEASURE IN PATIENTS WITH TRAUMATIC BRAIN INJURY IN AN ACUTE NEUROLOGICAL REHABILITATION SETTING

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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 2015

DECLARATION

I, Alison Louise Camp, declare that this research report is my own work. It is been submitted for the degree Master of Science in Occupational Therapy at the University of Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.



(Signature of Candidate)

22 day of May,2015

Abstract

Acute neurological rehabilitation aims to reduce the burden of care of patients with TBI and increase their activity participation. Weekly feedback to funders of private rehabilitation facilities using appropriate outcome measures is required.

This study compares the Functional Independence Measure™+Functional Assessment Measure (FIM™+FAM) with the Activity Participation Outcomes Measure (APOM) responsiveness to change in TBI patients in the acute neurological rehabilitation phase of recovery.

A quantitative, prospective, longitudinal design was used. Patients were scored weekly on both outcome measures.

No significant difference was found between the responsiveness of the two measures. Both measures showed change in activity participation (APOM) and reduction of burden of care (FIM™+FAM). The relevance of the APOM to the TBI population was good with a correlation above 0.8 with the total FIM™+FAM.

The APOM benefitted occupational therapists and the patient by assisting with goal setting and quantifying changes that the FIM™+FAM did not capture adequately. It is recommended that the APOM be used in future at the study site.

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My husband, Gerald who had to keep the home fires burning through these past few years of study. Your love and support made it ultimately possible. My gratitude and love to you is immeasurable.

Dedication

This research is dedicated to my parents Stan and Sheila Pridgeon who have been an ongoing source of support throughout my life. Their education was limited by the times in which they were born. They have striven to assist their children in every way to reach their full potential.

Table of Contents **Page**

Declaration i

Abstract ii

Acknowledgments iii

Dedication iv

Table of contents v

List of tables vii

List of figures vii

Appendices vii

Definition of terms viii

Abbreviations ix

Chapter 1 Introduction and background 1

1.1 Introduction 1

1.2 The research setting 3

1.3 Statement of the problem 4

1.4 Purpose of the study 5

1.5 Aim of the study 5

1.6 Objectives 5

1.7 Hypotheses 6

1.8 Assumption 6

1.9 Significance of the study 6

1.10 Organisation of this research 7

Chapter 2 Literature Review 9

2.1 Introduction 9

2.2 Traumatic Brain Injury 9

2.3 Epidemiology 10

2.4 Impact of Traumatic Brain Injury on Occupational Performance 12

2.5 Outcome Measures 14

2.6 Conclusion 22

Chapter 3 Methodology 24

3.1 Introduction 24

3.2 Study Design 24

3.3 Study Site 25

3.4.1 Study Population 25

3.4.2 Study Sample 25

3.4.2.1 Inclusion and Exclusion Criteria 25

3.4.2.2 Sample Size 26

3.5 Procedure of study 26

3.6 Measuring instruments 27

3.7 Data Analysis 29

3.8 Ethical Considerations 31

Chapter 4 Results **33**

4.1 Introduction 33

4.2 Demographics of the sample 33

4.3 Comparison of responsiveness between the APOM and the FIM™+FAM 34

4.4 Trends in change after intervention 35

4.5 Relevance 37

4.6 Conclusion 40

Chapter 5 Discussion **41**

5.1 Introduction 41

5.2 Demographics 41

5.3 Comparing responsiveness between the Activity Participation Outcome Measure and the Functional Independence Measure™ and Functional Assessment Measure 43

5.4 Trends in changes after intervention 44

5.5 Relevance of the Activity Participation Outcomes Measure in Traumatic Brain Injury 47

5.6 The use of outcome measures on a weekly basis 50

5.7 Limitations of the study 51

5.8 Recommendations for future studies 52

5.9 Conclusion 52

Chapter 6 Conclusion 53

References 55

List of Tables

Table 3.1 Comparison of the APOM and FIM™+FAM 28

Table 3.2 Methods of data analysis for each study objective 30

Table 4.1 Demographic table showing gender and age ranges 33

Table 4.2 Comparison of numbers of males and females with mechanism of TBI 34

Table 4.3 Comparison of age ranges and mechanism of injury 34

Table 4.4 The dependent t-Test between changes measured by the APOM and FIM™+FAM 35

Table 4.5 Correlations between the dependent and independent variables 37

Table 4.6 Correlations between the raw scores of the domains of the APOM and the domains of the FIM™+FAM 38

List of Figures

Figure 1 APOM and standardised response means of clients with TBI 36

Figure 2 Correlation between APOM Affect and total FIM+FAM 39

Figure 3 Correlation between APOM Motivation and total FIM+FAM 39

Figure 4 Correlation between APOM Role Performance and total FIM+FAM 40

Appendices

Appendix A	APOM Scoring Sheet	61
Appendix B	APOM Spidergraph (Example)	62
Appendix C	FIM™+FAM Scoring Sheet	63
Appendix D	Spidergraph of FIM™+FAM (Example)	64
Appendix E	Ethical Clearance Certificate	65
Appendix F	Institutional Approval Letter	66
Appendix G	Information Letter and Consent Slip	67

Definition of Terms

Activity Participation – The nature and extent of a person's involvement in life situations in relation to impairments, activities, health conditions, and contextual factors.(1)

Acute Inpatient Rehabilitation – The rehabilitation of patients who are unable to be discharged safely home from a medical perspective. They still require 24 hour nursing care and medical monitoring.(2)

ADL – Activities of Daily Living. Activities or tasks that a person does every day to maintain personal care.(3)

Effect size – The amount of change that occurs in a patient from baseline assessment until the final assessment of specific outcomes after intervention.(4)

IADL – Instrumental Activities of Daily Living. Complex activities or tasks that a person does to maintain independence in the home and community.(3)

Occupational performance – Ability of individuals to satisfactorily perform purposeful daily activities (occupations). This involves the dynamic transaction between the client, the context, and the activity.(3)

Outcome Measure – An instrument that is used to objectively determine the baseline function of a patient at the beginning of treatment. Once treatment has commenced, the same instrument is used to determine progress and treatment efficacy.(5)

Responsiveness – The capacity of a measure to detect meaningful change over time.(6)

Relevance – The ability of the instrument to evaluate relevant aspects in patients which lead to improvement in their health status.(7) In this study, 'relevance' refers to the capacity of the Activity Participation Outcome Measure (APOM) to capture activity participation deficits in patients with traumatic brain injury that would lead to improvement in their functional independence.

Standardised response mean – This is one of several effect size indices used to gauge the responsiveness of a measure to clinical change.(8)

Abbreviations

ADL – Activities of Daily Living.

APOM – Activity Participation Outcomes Measure

AusTOMs – Australian Therapy Outcomes Measure

COID – Commissioner for Occupational Injuries and Disability (Workman's compensation in South Africa)

COPM – Canadian Occupational Performance Measure

CVA – Cerebral vascular accident

DRS – Disability Rating Scale

FIM™+FAM- Functional Independence Measure and Functional Assessment Measure

GOSe – Glasgow Outcome Scale - extended

IADL – Instrumental Activities of Daily Living.

IALCH – Inkosi Albert Luthuli Central Hospital

LMIC – Low to middle income countries

LOS – Length of stay

MBA – Motor bike accident

MDT – Multidisciplinary team

MVA – Motor vehicle accident

NPO – Non-profit organisation

SRM- Standardised response mean

SCI - Spinal Cord Injury

TBI – Traumatic Brain Injury

VdTMoCA – Vona du Toit Model of Creative Ability

Chapter 1 Introduction and background

1.1 Introduction

"If a man has lost a leg or an eye, he knows he has lost a leg or an eye; but if he has lost a self—himself—he cannot know it, because he is no longer there to know it."(9)

Oliver Sacks captures the essence of a person with Traumatic Brain Injury (TBI) with these words – the loss of the sense of oneself. This is seen in practice from the acute phase of recovery often to the end of the person's life.

Traumatic Brain Injury has been referred to as a silent epidemic. The impact of even a minor TBI can lead to lifelong difficulties for a person with being a productive and independent member of society. These difficulties may not be obvious to the man in the street. The result is that the person with the TBI finds it difficult to fit in socially, in the formal work sector and even maintain personal, intimate relationships with their family. Family members often feel that they no longer have the person with them that they once had.

Management of TBI commences at the site of the trauma in an attempt to prevent secondary brain damage from hypoxia.(10) This depends on the immediate implementation of the basic principles of acute trauma management.(10)

The policy of most national health systems is to admit patients to neurocritical care beds at trauma units, regardless of whether the patient requires neurosurgical intervention.(11) The reality differs from the policies, particularly in low and middle income countries (LMIC) such as South Africa. A recent study done at InKosi Albert Luthuli Central Hospital (IALCH), showed that for every five patients referred who required neurocritical care beds, two were not accepted due to limited resources.(11) Patients with suspected TBI in KwaZulu-Natal are scanned in their regional hospitals (when scanning equipment is available) and the scans sent via telemedicine to IALCH where guidance is given for their management. Those requiring neurosurgical intervention are transferred to IALCH.(11)

The rehabilitation of patients with TBI is an entire subject of its own. Patients in the public health sector are sent back to their regional hospitals for further management if they have been admitted to the central hospital (IALCH). Once stable, they are discharged home from the regional hospital. Rehabilitative intervention in the regional hospital is limited and follow-up post discharge is often constrained by therapists' high caseloads, their knowledge and experience of working with persons with TBI and transport costs.(12)

In the private sector, resources in KwaZulu-Natal are also limited. There is one 50 bed inpatient rehabilitation centre that caters for primarily neurological disorders. This unit services the entire province of private patients and in addition draws from the eastern part of the Eastern Cape due to the limited private and state specialists in these areas. Patients from these areas travel to Durban in KwaZulu-Natal for neurological care as required.(13) Medical aids limit what they are prepared to pay for. Community resources are limited to a few non-profit organisations (NPOs) which cater for a wide variety of conditions. There is only one NPO specifically catering for patients with brain injuries in the province. Headway-KZN, offers outpatient therapy, support and social stimulation.(14)

The need to provide assistance for persons with TBI from all aspects: medical, rehabilitative, social and psychological, across the lifespan is a challenge. A life has been saved. The work of the rehabilitation team is to help to improve the quality of that life and the people involved in that life.(15) The question however has to be asked – what is quality of life? What is the standard by which it is measured and how can it be measured objectively? Is it income, reduction of physical dependence, contribution to society or social interaction?(15)

A number of studies have shown that attaining independence in activities of daily living (ADLs) and instrumental activities of daily living (IADLs), an active social support structure and gainful occupation are all contributors towards attaining a satisfactory quality of life post TBI.(16-18)

Early intervention has been shown to improve functional outcomes in persons with TBI.(19) Intervention from a co-ordinated multidisciplinary team (MDT) has been shown

to be more effective than uncoordinated treatment.(20) Intervention whether in the private or public sector is dependent on funding and cost effectiveness. Evidence of progress needs to be provided and demonstrated through the use of appropriate outcome measures.

1.2 The research setting

A private rehabilitation unit in KwaZulu-Natal with a 50 bed inpatient unit which has a primary focus on neurological rehabilitation was the research site. Patients admitted typically present with TBI, Cerebral Vascular Accidents (CVA), Spinal Cord injuries (SCI), polytrauma, and other medically complex conditions. Patients are typically admitted once medically stable and when they are ready to begin an intensive rehabilitation process from a MDT.

For occupational therapists within that MDT, their prime focus of intervention is aimed at patients regaining health and participation in life through engagement in everyday activities. These domains incorporate self-care tasks, mobility at home, basic communication, survival skills (IADL), rest and sleep, work, leisure and social participation.(21) The overriding outcome of occupational therapy is thus to facilitate activity participation in all areas of occupational performance within the context of the resulting disability so as to increase independence in the areas mentioned above. If independence improves, it reduces the burden of care of the patient in the longer term. Therefore increase in independent functioning in occupational performance areas is the inverse of burden of care.

Funding for such rehabilitation comes from medical aids, workman's compensation (Commissioner for Occupational Injuries and Disease - COID) and self-funding. There is therefore a need to demonstrate efficacy of treatment to funders, families and the patient themselves by demonstrating progress through changes in levels of functioning.(22) However patients who have suffered a TBI are often slow to demonstrate easily quantifiable change in occupational performance and functional independence, hence there is a need for a tool that is sufficiently responsive to record minor changes within the various domains of occupation. Length of stay within the

rehabilitation unit is dependent upon the ability to demonstrate progress as well as funder criteria of in-patient rehabilitation.

Measuring change in the acute phases of TBI rehabilitation is complex.(22) Unlike a CVA which is often a localised injury, a TBI is generally more diffuse.(23) This indicates involvement of multiple neurological factors as well as personality, socioeconomic status and environmental influences and performance skill dysfunctions which impact on all domains of life. These client factors and performance skill dysfunctions are often interdependent, such as short term memory being dependent on the client's ability to attend and concentrate.(22)

1.3 Statement of the problem

In the rehabilitation unit the Functional Independence Measure™ and Functional Assessment Measure (FIM™+FAM) is the outcome measure that is used on a weekly basis to indicate change in the independent functioning of patients to the MDT and funders. The FIM™+FAM is measuring independent functioning on the higher end of the scale (highest score equals 7) and burden of care on the lower end of the scale (lowest score being 1).(24-26) During the weekly MDT meetings in which progress is discussed, health care professionals frequently mention that progress has been observed but is unable to be demonstrated as a numerical change on the FIM™+FAM. This results in a patient being rated on a low score of independency for many weeks despite there being changes or improvements within that level. This then has led the researcher to look for an alternative outcome measure that would be more responsive to changes.

The Activity Participation Outcome Measure (APOM) has been developed in South Africa as an outcomes measure that is valid and reliable in the field of mental health.(27) It has yet to be used in the field of neurological rehabilitation. The theoretical framework that underpins it; the Vona du Toit Model of Creative Ability (VdTMoCA) can be applied to patients who have suffered a TBI, as a result of the sequeale that encompasses all areas of life following TBI.(4) The responsiveness to clinical change of this outcome measure with these TBI patients is however unknown.

The construct measured by the FIM™+FAM and APOM has certain similarities but also differences. Independent functioning as measured by the FIM™+FAM is a concept used by all members of the MDT and refers to the ability of the person to perform those tasks and activities in everyday life while the construct measured by the APOM namely activity participation is more often used by occupational therapists. The construct of activity participation also measures ability to perform daily tasks but classifies activities of daily life into occupational performance areas. Other concepts central to occupational therapy are also included in activity participation namely purposeful use of activity, performance of roles in daily life, level of interest and motivation to perform tasks.(28) To date no investigations were done to determine whether occupational therapists may indeed find an outcome measure that includes unique aspects of the profession more relevant and responsive than generic outcome measures like the FIM™+FAM.

1. 4 Purpose of the study

The purpose of this study is to find an outcome measure for occupational therapists that will measure change in activity participation in traumatic brain injuries in an acute neurological rehabilitation setting. The outcome measure must be responsive to clinical change and point to the unique contribution of occupational therapists towards neurological rehabilitation. Two outcome measures namely the FIM™+FAM and APOM will be compared for this purpose.

1.5 Aim of the study

To compare the APOM and the FIM™+FAM for responsiveness to change in the independent functioning of patients with TBI who were treated in a private rehabilitation setting during their hospitalisation.

1. 6 Objectives

1.6.1 To compare the responsiveness to change of both outcome measures in order to determine differences between each measure in determining activity participation and independent functioning of patients with TBI.

1.6.2 To describe the trends in change in TBI in terms of activity participation as measured by the APOM as well as independent functioning as measured by the FIM™+FAM during the acute phase of neurological rehabilitation.

1.6.3 To describe the relevance of the use of the APOM in persons with TBI.

1.7 Hypotheses

Null Hypothesis

The APOM is no more responsive to demonstrating change of activity participation than the FIM™+FAM during the acute phase of neurological rehabilitation in persons with TBI.

Alternate Hypothesis

The APOM is a more responsive outcome measure to demonstrating change of activity participation in persons with TBI than the FIM™+FAM during the acute phase of neurological rehabilitation.

1.8 Assumption

The assumption made for this study is that the APOM is an outcome measure that can be utilised with patients who have suffered a TBI and are in the acute phase of rehabilitation, despite it having being developed for use in the mental health care field. It is assumed that because volition in a person with TBI plays an important role in their recovery process and that the APOM is founded on the theoretical tenets of Creative Ability, namely volition and action, that it will be an appropriate outcomes measure for TBI.

1.9 Significance of the research

A psychometrically sound tool that is sufficiently responsive to change in activity participation in patients, who present with TBI is required in the neurological rehabilitation unit where the researcher works.

There is a need to add to the international literature on neurological rehabilitation of persons who have suffered a TBI, particularly from a South African perspective. TBI is an ever burgeoning problem particularly in LMIC. In order to provide appropriate interventions and motivate for funding for such interventions, it is necessary to

demonstrate change in occupational performance of patients undergoing neurological rehabilitation.

In addition, occupational therapists are being called upon to justify their profession by utilising evidence based outcome measures. The APOM is "Proudly South African", developed by an occupational therapist and has been used primarily in the field of mental health care. As a health professional, one needs to be accountable to not only to oneself and colleagues but also to the funders, families and patients themselves.(29) An appropriately responsive outcome measure would assist in demonstrating that accountability.

If the APOM is effective in demonstrating incremental change in patients with TBI in the acute phase of neurological rehabilitation, it will add to evidence of the effect of rehabilitation and enhances the profession's credibility of being effective agents of change in persons with TBI.

1.10 Organisation of this research

This research report will be laid out in five chapters. The chapters are introduced and summarised below.

Chapter 1 introduces the background and need for the study. The aims and objectives are also presented in this chapter.

Chapter 2 provides a literature review about the incidence of TBI, causes, effects, and current outcome measures in use.

Chapter 3 describes the methodology of the research. A quantitative, prospective, longitudinal study design was selected. The procedure and methods of analysis are presented as well as the ethical considerations.

Chapter 4 reports on the results of the study. The responsiveness of the FIM™+FAM and APOM are compared. Trends that emerged from analysis of the raw data are documented through tables and graphs. Trends in activity participation are described as captured by the APOM. The ability of the two instruments (APOM and FIM™+FAM) to detect real change in activity participation and independent functioning are described.

Chapter 5 discusses of the implications of the results. Recommendations and limitations of the study are also described.

Chapter 6 concludes this report by providing an overview of the study and a commentary on the use of outcome measures

Chapter 2 Literature Review

2.1 Introduction

This chapter is a review of the current literature available that has been relevant to this study. The review covers literature pertaining to TBI with a particular emphasis on the South African context. In addition, a review of the common outcome measures used, the need for outcome measures in rehabilitation and the need to demonstrate change as a result of intervention is discussed.

The literature search was conducted in the following databases: PubMed, Wiley Online library, Science Direct, PsycArticles, PsychiatryOnline and use of search engine Google Scholar. The search included all articles in English between 2000 and 2014. Other documents that are not classified as articles for instance position statement and government year reports on related topics were also included. The keywords used to focus the search were: Traumatic Brain Injury, neurological rehabilitation, outcomes measures, responsiveness to change, FIM™+FAM, Rancho Los Amigos, Creative Ability, APOM, epidemiology of traumatic brain injuries, quality of life. The term South Africa were used to narrow down the searches to publications that include South African populations but non-South African literature were also included.

2.2. Traumatic Brain Injury

In reviewing the literature on TBI and outcome measures used, a common thread emerges of the devastation that TBI wrecks on individuals, their families and their wider communities.

The scarcity of resources, human and organisational in South Africa and the difficulty with accessing those resources available, often leads to poor quality of life outcomes for the person who has suffered a TBI and their family.(30, 31) It becomes imperative then to try and ensure that early stage intervention happens, is appropriate to meet the needs of the patient and family, and that it is sustainable.

One of the ways that sustainability can be achieved is through demonstrating change in outcomes to funders of intervention. This needs to happen in both state and private facilities. The limited number of rehabilitation beds available in both the private and state sectors means that patients need to be demonstrably improving or alternative plans need to be made for their long term care.(32)

An appropriate outcome measure is required to demonstrate this change and on reviewing the literature, certain measures appear to have a greater sensitivity to demonstrate change in patients with TBI.(33)

The difficulty with using outcome measures to demonstrate change is that intervention tends to become dictated by what that outcome measure, measures. This then has the potential of not necessarily meeting all the patients' needs in the acute phase.

This literature review aims to look at the incidence, causes and outcomes of TBI in a South African context, as well as outcomes measures used to demonstrate change after rehabilitation in TBI.

2.3. Epidemiology

Traumatic Brain Injury is an increasing problem with an incidence of 150-170 persons per 100 000.(34) This has been linked internationally to the high incidence of road traffic incidents. The World Health Organisation (WHO) postulates that by 2020 TBI will surpass many diseases and become the major cause of death and disability globally.(34)

South Africa has no formalised TBI database and studies on the incidence and prevalence are lacking.(30) Bruns collected data on TBI in early 2000 and reported 360 cases per 100 000 population in South Africa in 2003.(35) This study highlighted the methodological difficulties of obtaining information in an environment of poor record-keeping, large volumes of patients, under resourced public hospitals and lack of funding for research and epidemiological studies.(30) South African statistics indicate that the greatest cause of TBI's is road traffic accidents followed by intentional trauma. In 2000 the homicide rate in South Africa was 9 times the global rate. In a 2006 study in the Cape Town Metropole, 25% of deaths in males aged 15yrs and above were ascribed to homicide. This highlights the intentional nature of trauma in South Africa.(36) A 2013 retrospective analysis based

in KwaZulu-Natal at the InKosi Albert Luthuli Central Hospital (IALCH) determined that the commonest causes of TBI for the province was assault followed by MVAs.(11) A 2014 study, reviewing 124 patients admitted at Groote Schuur and Tygerberg Hospitals between 2009-2011 found that the major cause of TBI was road traffic accidents (67%) followed by assaults (24%).(37)

In 2000 the annual costs of TBI in the USA were estimated at $60 billion dollars incorporating the medical expenses as well as loss of productivity in society. As more people survive TBI, the costs are expected to rise.(38) The death rate from TBI in the USA has decreased from 25/100 000 in 1979 to 19/100 000 in 1992. This declining death rate is ascribed to better acute management of TBI.(39) This declining number has led to the growth of survivors in a social and economic environment that has limited understanding of the needs of people with TBI.(39)

In a LMIC such as South Africa, this may not necessarily be the case as early intervention to prevent secondary injury from hypoxia, hypovolaemia and hypoglycaemia is dependent on early rapid response to maintain the patient's airway and provide an unbroken chain of care.(10) In a study reviewing the care of TBI patients at a busy regional hospital in Kwa-Zulu Natal, it was found that referral difficulties from peripheral hospitals were noted which delayed appropriate management. The study also demonstrated that the pathology of TBI being poorly understood which impacted on mortality and morbidity.(10)

In South Africa, as of 2010, there was a total of 780 beds available for acute physical rehabilitation in both private and state sectors. This data was obtained during electronic communication from Strydom, the national standards manager of a large private rehabilitative healthcare group in South Africa.(32) These beds are for varying diagnoses, not only TBI. With the figure mentioned of 360/100 000 for TBI, it is obvious that this availability falls woefully short of what is needed to meet the needs of persons with TBI in South Africa. The average length of stay in a private acute rehabilitation setting for patients with TBI is 35 days with an average cost of R168 000 to the funder in 2014.(32) In the South African healthcare environment where cost containment is actively driven, the costs of acute rehabilitation are alarming.

TBI in South Africa is an ongoing problem which appears to be increasing with violence related incidents, motor vehicle accidents, as well as pedestrian accidents.(11, 30) The impact on occupational performance is significant, including loss of life roles and the subsequent financial implications for families and communities that may prevail over a lifespan.

2.4. Impact of Traumatic Brain Injury on Occupational Performance

Traumatic Brain Injury may result in a wide range of limitations and restrictions that can encompass all domains of life. These may include motor problems as well as distinct cognitive, social, emotional and behavioural problems.(40, 41)

Motor problems may include any or all of the following: paralysis or paresis such as a hemiplegia, cranial nerve damage resulting in paralysis of eye muscles, swallowing difficulties, dysarthria, and vestibular reflex abnormalities.(15) Abnormal muscle tone, poor co-ordination of movement, loss of selective control of movement, poor balance, and loss of bowel and bladder control. There may be associated loss of the special senses, hearing, vision and smell.(15)

Eyssen describes occupational performance as the ability to choose, organise, and satisfactorily perform meaningful actions that are required to look after oneself, enjoy life and contribute to the social and economic web of a community.(42)

In the long term, the problems associated with the cognitive, social, emotional and behavioural domains are the most disabling and have a significant impact on occupational performances.(40, 41) These long term symptoms of TBI often contribute to a loss of the sense of one's self. This leaves a person feeling unsettled about who they are, where they are going and their roles in life. Depression and decreased motivation for participation in life is a consequence of the disruption in one's self and leads to a decline in occupational performance. People who have plateaued in their functional recovery following a TBI continue to struggle to rebuild their identity.(43) Outcomes at one year post injury have shown the most common problems to be difficulties with memory and problem solving, managing stress and emotional outbursts.(15)

Complications that may arise from a TBI are limitless, including risks associated from medical intervention itself.(15)

The cognitive and behavioural changes post TBI co-exist in a complex web with the person's premorbid personality characteristics. It is difficult to dissociate one from the other in the therapeutic process. Lezak refers to persons who have sustained a TBI as having been "characterologically altered".(44)

In the acute rehabilitative phase there is a focus on the restoration of competence in basic self-maintenance tasks such as eating, bathing, dressing and toileting. This may extend to basic survival tasks of basic meal preparation, use of communication devices such as the cell phone and basic money handling.(19) Behavioural issues may affect the patient's ability to participate at this stage in the rehabilitative process. Damage to the brain may result in an increase in irritability, aggressiveness and a loss of volition. As the patient increases in alertness so these behavioural issues may increase and together with reduced insight into their deficits often results in a patient that is difficult to manage.(19)

Depression is common in patients who demonstrate an increasing awareness into their limitations and the restrictions imposed on them by family and staff in the acute rehabilitative setting. It is important for the multidisciplinary team to be aware of this, and to appreciate the state of internal chaos and vulnerability of many patients with TBI at this stage of their recovery.(19)

Rehabilitation in both the acute and long term phases attempts to address the challenges that develop as a result of TBI. The World Health Organisation (WHO) has drafted guidelines on the need for access to rehabilitation, stating in Article 26, that "services must begin at the earliest possible stage, should be based on the multidisciplinary assessment of needs and strengths and should include provision of assistive devices and technologies."(45)

A Norwegian study found that a continuous chain of rehabilitation, beginning in the ICU phase and moving directly to acute rehabilitation was more cost effective and resulted in better health outcomes in the long term (five years) than a broken chain of rehabilitation where a patient has to wait for access to rehabilitation. (46)

Outcome studies indicate that in spite of rehabilitative efforts, many people with a TBI remain significantly impaired resulting in a high burden of stress to families and the wider community. The reasons for this are postulated as being due to the unique, epidemiological, pathophysiological, and neuropsychological characteristics of TBI.(39) Long term problems with memory, thought processes and physical and emotional health have been reported in a study which assess quality of life and participation in vocational and community life. The mean years since injury in this research was 28.8 years. Increasing injury severity showed a direct correlation with a decline in quality of life and participation in life.(47)

TBI occurs more frequently in young adult males, but the male/female ratio is shown to decline with increasing age reaching a 1:1 ratio by the age of 65years.(48) The mechanism of injury may differ between age groups and lead to different types of injury. The IMPACT study found that age is one of the strongest predictors of outcomes in TBI with older patients having poorer outcomes.(48)

Co-ordinated rehabilitation and community based support services over the life span of a person with TBI are required for successful outcomes.(47)

Community based support groups specific to persons with TBI are found in the major cities of South Africa, however access to ongoing therapy and facilitation for return to work is lacking. Watt and Penn found that only 32% of persons with TBI in South Africa who claimed financial compensation through the medico-legal system returned to employment (49). Very little research has been done on the economic burden that mild to moderate TBIs have on their families, their carers and society as a whole.(50)

2.5. Outcome Measures

In the rehabilitation of patients who have had a TBI, there is a need to demonstrate progress to justify length of stay as well as to demonstrate efficacy of clinical intervention.(22, 29) This is dependent on the use of valid and reliable measures of function.(22) The instrument chosen to evaluate an intervention must be able to capture the range of disablement in the population and detect clinically significant change in the outcome being measured.(22)

Occupational Therapy intervention is seen as a valuable and efficient component within the MDT, but without adequate information to demonstrate effectiveness of intervention, it is difficult to promote the need for such a service to funders and to other members of the health professional team. The paucity of scientific evidence renders a service vulnerable.(51)

In the clinical field of occupational therapy emphasis is often placed on assessments without empirical measurement and the evaluations of such assessments are usually vague, descriptive and lack validity.(51) Funders and consumers no longer accept vague descriptions of progress and occupational therapists are being actively challenged to prove the effect of their interventions. One of the ways to demonstrate the effectiveness of their interventions and to provide evidence of the importance of occupational therapy is through the use of outcome measures. The effectiveness of therapy is shown when a therapist can demonstrate that the change is due to the intervention and not due to spontaneous recovery.(52-54)

Turner-Stokes discusses criteria that need to be met for instruments in measuring outcome and states that they should have proven validity and reliability and must be sensitive to change (responsiveness). In addition they need to be relevant to the rehabilitation intervention.(55) Nichol adds that an outcome measure should be logistically simple to administer and should ideally be available at no cost.(56)

There is discussion in the literature as to whether responsiveness should be considered a separate property of a measure or whether it is an aspect of validity.(57) Terwee puts forth that there is lack of clarity in the literature about the definition of responsiveness and as a consequence there is inconsistency in the methods for calculating responsiveness and an inadequate approach for evaluating it.(57)

According to Terwee three categories of definitions have emerged in their research about responsiveness. Firstly that responsiveness is the ability to detect change in general. This could be any kind of change whether it is relevant or meaningful.(57) Secondly it can be more specifically defined as the ability to detect clinically important change. This is different from the first category in that it requires a subjective judgement on what is important to measure in the first place. (57) Thirdly, responsiveness can be defined as the

ability to detect real changes in the concept being measured. This links to the relevance of an instrument in the clinical setting for TBI.

Responsiveness is classically described by Guyatt and Kirschner, as the capacity of a scale to detect meaningful change over time.(6)

Outcome measurement in TBI has its challenges. It is not always possible to measure the intervention causing change, versus the spontaneously recovering brain.(55) Often there is a slow rate of recovery in the more severely injured and there is pressure from funders to justify the cost of rehabilitation. Simply noting that there is improvement in quality of life is insufficient. Environmental facilitators such as family support, an accessible environment, or inhibitors such as poverty have a significant role in affecting the outcome of rehabilitation.(55)

Further difficulties noted in outcome measurement with TBI include poor definitions in measures commonly used, a lack of responsiveness to change of the measure used, and an inability to evaluate patients who are aphasic and limited domains of functioning within the measure. (58)

There is also an assumption that persons with a TBI have been “normal” pre-injury. However there has been sufficient evidence that many persons with a TBI have had a prior brain injury, drug dependence issues or have a concomitant psychiatric diagnosis.(56) This has resulted in researchers modifying the scoring of outcome measures in order to take these pre-morbid factors, such as problems associated with a premorbid diagnosis of attention-deficit hyperactivity disorder (ADHD) into account and attempt to deal with the potential pre-existing factors associated with ADHD in the post TBI assessment.(56, 59)

There is disagreement in the literature as to when to begin administering an outcome measure. One school of thought is that the earlier a measure can be administered to assess a group of patients, the better. This assists with giving information around level of care required as well as preventing drop–out and loss for follow up in clinical trials. The other school of thought believes that there needs to be recognition that patients with a TBI in the acute phase are often still stabilising medically and that measures used may not

be a true reflection prognostically.(56) Spontaneous recovery and concomitant injuries may be influencing factors in the patients presentation and scoring on an outcome measure.(56)

There is a strong move to using outcome measures in TBI research that are linked to the levels of the International Classification of Functioning, Disability and Health (ICF), that is function, activity and participation.(60) TBI rehabilitation aims to enhance participation, thus the measurement of participation is important.(61) Stiers discusses the conceptual differences between participation and quality of life. He concludes that an increase in participation levels is correlated with an increase in quality of life thus quality of life measures can be helpful in studying participation levels.(61) The researcher believes that the reverse is also true. By using an outcome measure that will demonstrate change in participation levels, a change would be detected in quality of life.

Emerging measures that are being looked at in TBI outcomes research are those focusing on health related quality of life measures, such as the Quality of Life after Brain Injury (QOLIBRI), Quality of life in Neurological Disorders (Neuro-QOL), and Traumatic Brain Injury-Quality of Life (TBI-QOL).(60) These measures are self-reported. However, these measures appear to be best utilised post discharge from the acute rehabilitation setting, due to acknowledged difficulties in using self-reported quality of life measures in a patient population that is often cognitively compromised.(61)

Glasgow Outcome Scale-extended (GOSe)

Common functional measurement scales used in TBI patients include the Glasgow Outcome Scale-extended (GOSe).(62, 63) This measure has being recommended as the gold standard to be used in TBI trial studies.(56, 60) It is used in both the acute care as well as rehabilitative phases. Most studies have used it at 6-12 months post injury. The GOSe is an eight level scale in which the levels are broadly defined. The levels range from 1 representing death, to 8 representing the upper range of good recovery in which any deficits remaining have no disabling effect on return to work capacity. It is acknowledged that its dichotomous nature leads to a lack of responsiveness.(56) The QOLIBRI has been demonstrated to be sensitive with the GOSe scores.(64)

FIM™+FAM

In the acute rehabilitative phase the FIM™+FAM has been widely accepted as a measure that is valid and reliable. Originally developed as the FIM™, it was found that it had a ceiling effect that limited its usefulness in detecting subtle changes. The FIM™ was developed as it was felt that Barthel Index was not sufficiently sensitive to show change in its three levels.(62) The FAM was added as adjunct to the FIM™ in order to lessen the ceiling effect. Together they are known as the FIM™+FAM.(33) The FIM™+FAM is a 30 item scale in which each item has seven levels on which to be scored. It reflects changes in behaviour from dependence to independence. The functional abilities are rated on an ordinal scale and the numbers assigned to represent the ratings do not necessarily represent equal distances between them.(65) The FIM™+FAM is designed to be scored within 72 hours of admission and scored again within 72 hours before discharge.(66)

In the rehabilitation unit where the research is undergoing, it is the policy of the unit to score patients using the FIM™+FAM on admission, weekly and on discharge. This is the policy of all the rehabilitation units that fall within the healthcare group. This is funder driven. Weekly reports are required to be generated and submitted to the funder to demonstrate progress and update length of stay. For the TBI population in rehabilitation, this becomes difficult as the FIM™+FAM that is used, has been found by the MDT to not always demonstrate the subtle changes that occur in the early phases of recovery. This results in the patient being rated on a low score of dependency for many weeks, despite there being changes within that level. The use of the FIM™+FAM on a weekly basis when it has not been designed for that, is an example of modifying an outcome measure to suit the circumstances.

The positive aspects of the FIM™+FAM in the research environment are its ability to be used by the MDT. It is also able to be used across differing diagnoses. However these qualities of the FIM™+FAM appear in the researcher's view to contribute to a lack of responsiveness to change in patients with TBI with particular reference to occupational performance.

Clinicians who wish to use the FIM™+FAM need to undergo training and credentialing.(65) This enhances intra-and inter-reliability of the instrument.

Barthel Index (BI)

The Barthel Index is referred to frequently in studies pertaining to the TBI population in the acute phases.(67, 68) This instrument incorporates ten items which include domains of self-care, functional mobility and gait. It has three broad levels of measurement within each domain: dependence, needing help and independence.(69) Criticism of the Barthel Index is that it focuses on the physical aspect of recovery in TBI almost exclusively and does not consider the neuropsychological sequelae.(69) Houlden determined that the Barthel Index and the total physical FIM™ scores showed similar scores, whilst the cognitive FIM™ score was the least responsive to change.(22)

Rancho Los Amigos

The Rancho Los Amigos levels of Cognitive Functioning Scale is a medical scale used to assess persons with a closed head injury including TBI.(67) It uses behavioural observations to categorise a patient's level of cognitive function.(19) It helps clinicians to discuss a patient's level of cognitive function amongst themselves and with families in order to develop appropriate rehabilitation interventions. The first three levels of the scale describe the response to stimulation and the environment of persons emerging from coma.

As for the FIM™+FAM, Barthel and GOS-E, the Rancho Los Amigos Scale is an ordinal scale.(70) Ordinal scales allow for ranking but do not include equidistant points between the scores.(29) Not all patients who survive TBI progress through all the levels, and they may also skip levels.(70) As the Rancho Los Amigos Scale is more descriptive in nature in its various levels, it is difficult to use it as a quantifier when working with funders of rehabilitation services.

Disability Rating Scale (DRS)

The Disability Rating Scale is a widely used measure in the literature around TBI rehabilitation.(71) It is based on a structured interview and is believed to be useful in patients with a moderate to severe TBI. (60) It is intended to measure general functioning

during the patients' course of recovery. The DRS provides a single score based on level of arousal, cognitive ability to perform basic ADLs which includes eating, grooming, toileting, home independence and employability.(60) The DRS has been found to be less responsive to small changes in TBI, particularly with those who are classified with a mild TBI.(72)

Outcome measures that have been specifically developed for occupational therapists include the Canadian Occupational Performance Measure (COPM) and the Australian Therapy Outcomes Measures-occupational therapy (AusTOMS-OT).

AusTOMs

The AusTOMs(71) was developed with the goal to develop a valid and reliable measure of therapy outcomes for the three largest allied health professions in Australia; occupational therapy, speech pathology and physiotherapy.(52) It was designed to measure therapy outcomes separately for the various disciplines.(52) The AusTOMs-OT has been shown to be a valid and reliable outcome measure for all clients across a variety of settings including rehabilitation.(73) There are 12 domains in the AusTOMs-OT scale which incorporates mobility and transport, learning and application of knowledge, domestic life, use of transport, work and education, self-care and community integration.(64) Each of these require a rating of four domains of client function based on the ICF that is, Impairment, Activity Limitation, Participation Restrictions and Wellbeing/Distress.(52) Each of the domains are rated on an 11-point ordinal scale which incorporates half points.(52) Clinicians have been found to use the half points as a means to increase the measures responsiveness.(52)

Canadian Occupational Performance Measure (COPM)

The COPM is an evidence based outcome measure that has been designed to measure a patient's self – perception of their performance in everyday living over time.(74) It is designed to prioritise issues that restrict a patient's performance in everyday day living. A strength of the measure is its broad focus on occupational performance in all areas of life including self-care, leisure and productivity throughout the patients' lifespan and their personal life circumstances.(74) Literature in the use of the COPM in the acute phase of rehabilitation has been scarce. The fact that it is a measure that is based on the patients'

self-evaluation is a possible reason why for it not been used in the acute rehabilitative phase, as the patients' level of arousal, cognition and ability to perceive their circumstances is often limited during this time.

Activity Participation Outcome Measure (APOM) and South Africa

There is a dearth of outcome measures that have been validated and are reliable for the South African population particularly in the field of mental functioning for use in occupational therapy.(27) The development of the APOM occurred to address this need.(27) Although developed for use in mental health settings, the APOM could arguably be used in patients who have suffered TBI because it measures outcomes related to process or cognitive skills and communication skills. Due to the extensive cognitive fallout and loss of active participation in life that afflicts the majority of patients with TBI, the APOM might be an appropriate outcome measure for TBI. This assumption however needs to be investigated.

The APOM has been developed with the VdTMoCA as its theoretical framework.(27) The central concept of Creative Ability is volition and this is comprised of two intrinsically linked components, motivation and action.(75) Motivation is the inner drive that initiates occupational behaviour.(75) Motivation is dynamic and is different at different times of life and the stages of development of one's life. Action is the translation of motivation into physical and mental effort that produces occupational behaviour and outcomes.(75)

The Model of Creative Ability has outlined nine sequential levels of corresponding motivation and action. As a person moves through the levels of motivation and action, the occupational performance in that person increases due to the acquisition of a wide range of skills and behaviours.(27, 75) Creative Ability describes how a person develops from existence to active societal contribution along a continuum.(75) This continuum may be interrupted through disease or trauma anywhere along its development resulting in that person regressing to a lower level of action (participation).

The APOM has been developed using the first six of the nine levels of Creative Ability.

The APOM measures eight domains. These are: process skills, communication/interaction skills, life skills, role performance, balanced life style, motivation, self-esteem and affect.

Within each domain, there are several items that represent that domain.(4) Each of the domains is measured on a scale of 18 increments. These 18 increments are divided into six levels of activity participation. Each level of activity participation comprises three phases, patient directed, therapist directed and transitional phase into the next level.

These phases indicate the support or assistance a person needs within a specific level. There are thus three phases within each level which allows for the therapist to demonstrate change within each level. This is crucial, particularly for patients whose progress is limited or slow due to the nature of their injury or disease process.

This progress is important to note in TBI patients as their progress may be subtle and difficult to quantify. Casteleijn reported on the ability of instruments, based on the levels of Creative Ability to be used in measurement.(76) Her findings indicated that the levels of Creative Ability and the subdivision of each level into phases, are valid indicators of the increasing amount of ability of a patient.(76) The scores of Creative Ability instruments (like the APOM) follow a linear or hierarchical pattern. This type of pattern is easy to understand for funders whose decision makers are often from the non-rehabilitative field and who may have limited understanding around length of stay and the need for on-going therapeutic services in patients who show limited improvement in scores currently used.

The APOM is designed to have a minimum of two ratings, preferably three.(4) On admission, prior to discharge and for patients with a longer length of stay a mid-point rating is advisable.

The APOM has yet to be used in the field of neuro-rehabilitation. The theoretical constructs that underpin it, the VdTMoCA has already being linked to other measures used in identifying change in patients with TBI, namely the Rancho Los Amigos Scales.(77)

Hence there is a reasonable assumption that the APOM will reflect progress related to change in the functioning of patients with TBI.

2.6 Conclusion

TBI is a disabling condition that knows no boundaries in terms of race, religion, age, or sex. TBI may have lifelong, crippling consequences for the patient. The consequences extend into the family and wider community, as often lifelong care is required and the

loss of premorbid occupational roles has a profound negative economic effect. Reducing the burden of care by facilitating a resumption of former life roles is a primary focus of occupational therapy in the acute rehabilitative setting. The financial cost of rehabilitation is high and funders demand progress to justify length of stay. There is a need for an outcome measure that is sensitive to changes, ideally on a weekly basis. The current measure in use at the research setting has been found by the MDT to lack sensitivity to change and have a ceiling effect that limits its usefulness.

The research outlined in the following chapters aims to compare the responsiveness of the APOM to that of the FIM™+FAM in quantifying incremental changes in patients with TBI in the acute rehabilitation setting to establish if the APOM is a more responsive measure to clinical change.

Chapter 3 Methodology

3.1. Introduction

This chapter provides an outline of the study and the methods used to collect the data. It includes the study design, study site, study population and criteria for inclusion into the study. The methods for data analysis are described. The measurement tools utilised and ethical considerations are discussed.

3.2. Study Design

The study is a quantitative, prospective, longitudinal study that compared the responsiveness to change of the FIM™+FAM and the APOM in measuring progress in the independent participation in occupational performance of patients who have suffered a TBI and who are being treated in an acute neuro-rehabilitation setting.

The design of the study has been appropriate because the researcher has aimed to quantify numerically the changes in the patients' independence in mental functioning and activity participation on a weekly basis from admission to discharge.

The study is prospective and has made use of new data in an attempt to establish the responsiveness of the two outcome measures in detecting change in patients recovering from a TBI.(29) Prospective studies attempt to establish the outcome of an event or what is likely to happen.(29) In this study the researcher needed to wait for intervention to occur prior to being able to score patients on the two outcome measures being used.

A longitudinal approach has been taken and the same data was collected from the study sample at predetermined intervals, in this study, on a weekly basis.(29) Thus the study has been longitudinal in nature by the virtue of compiling weekly data from admission to discharge, using both outcome measures.

Kumar in his text on research methodology highlights the main advantage of a longitudinal design of allowing the researcher to measure the pattern of change and obtain factual information, requiring collection on a regular or continuing basis, thus enhancing its accuracy.(29)

3.3. Study site

The site of the research was a 50 bed private rehabilitation unit in Durban, KwaZulu-Natal. It is a preferred provider of rehabilitation for the larger medical aid schemes in the country. It draws its patient population from the whole of the province as well as the eastern part of the Eastern Cape Province.

The unit is designated primarily as an acute neurological rehabilitation unit that provides services on an inpatient basis only. It is a 50 bed unit and caters for all age categories. The majority of the patients present with CVA, TBI and SCI. They are transferred from the acute medical setting once deemed medically stable by the referring physician and can tolerate up to three hours of therapeutic intervention daily.

The rehabilitation unit is attached to an acute hospital in Durban which is classed as a Level 1 trauma hospital and has neurosurgical services available.

3.4.1. Study Population

The study population from which the research sample was drawn, represented all the patients admitted to the rehabilitation unit from the period beginning September 2013 to end September 2014. A definitive time period was required in order to complete the research timeously within the framework of the academic master's programme.

3.4.2. Study Sample

The subjects in the study were those who had suffered a TBI and consented to participate in the study. Thus in this study the sample used was total population purposive sampling.

3.4.2.1. Inclusion and Exclusion Criteria

All subjects were required to be over the age of 18 years, as the APOM as well as the FIM™+FAM have been developed for a population 18 years and older.

Patients who presented with a TBI as diagnosed by the referring medical practitioner to the research site and admitted between 1 September 2013 and 30 September 2014 were included.

Patients who were declared medically unstable by the rehabilitation neurologist were excluded from the study due to inability to participate in the rehabilitative process.

3.4.2.2. Sample Size

According to the Raosoft sample size calculator, a power calculation determined that 28 patients were required for the study.(78) The margin of error was set at 5% and the confidence level at 95%. The population of TBIs at the rehabilitation unit is approximately 30 annually. The recommended sample size was calculated to be 28. The number of patients that were available for the study was 28 which represented all the patients classified as having had a TBI and admitted for neurological rehabilitation during the time period stipulated.

3.5. Procedure of the study

Patients are referred by doctors from the acute medical setting to the rehabilitation unit via case managers. The case managers assess the patients either physically or telephonically in the case of extraordinarily long distances from the unit, such as Northern KwaZulu-Natal, Eastern Cape, or Lower South Coast. The patient is then discussed with the rehabilitation unit's management team to determine suitability for admission and based on this outcome, a motivation is sent to the funder for authorisation to admit to the unit once a bed is available and the patient is medically stable.

Once patients are admitted to the unit, they are then assessed routinely by the entire team of therapists. This will include assessments by the physiotherapist, occupational therapist, speech therapist, social worker, dietician, psychologist, nursing and the medical doctor.

The assessments are conducted over a 72 hour period following which an admissions report is drafted and sent to the funder reporting on admission findings, short term and long term goals of intervention and requested length of stay in order to achieve those goals.

In the unit the routine outcome measure used is the FIM™+FAM which is scored by the entire team on admission, weekly and on discharge. For the purposes of this study the

APOM was added to this and scored by occupational therapists. The therapists who utilised this had been trained in the APOM as well as the FIM™+FAM.

The assessments utilised to determine baseline admission scores were participation in self-care tasks, functional motor ability, following of routine instructions pertinent to basic nursing care and observed interactions with family members, nursing staff and other patients.

On a weekly basis, participation in ADLs and IADLs was used to score patients on both the APOM and FIM™+FAM. The length of stay varied among the patients due to the benefits available from the different funders. Funders authorise length of stay based on demonstrable progress as well as the level of the medical plan the patient has.

Scoring by the treating therapists was entered onto a hard copy of both the APOM and FIM™+FAM scoring sheets (see appendices A and C). The APOM was then entered into the online database by the researching therapist while the FIM™+FAM data was captured by the rehabilitation secretary into their online database.

The hard copy of the data was then entered onto an Excel spreadsheet by the researcher.

3.6 Measuring instruments

As mentioned above, the APOM and FIM™+FAM were used to track change in activity participation and independent functioning respectively. The psychometric properties of these instruments have been reported in the literature. A summary is done in table 3.1 From this comparison of the measuring instruments used in this study, it is evident that the APOM has good psychometric properties but only with mental illnesses while the FIM™+FAM showed good psychometric properties with neurological, general medical and orthopaedic conditions. There is a vast amount of literature that report on the use of the FIM™+FAM but the opposite is true for the APOM. The APOM is a relative newly developed outcome measure while the FIM™+FAM has been developed in the 1980's with many studies reporting on its validity and reliability.(26, 55, 65, 79, 80)

Both these measures use a sum score for the items in the different domain as well as a sum score of the domains. This might be viewed as violation of the use of ordinal scales.

Table 3.1 Comparison between the Activity Participation Outcome Measure and Functional Independence Measure™ and Functional Assessment Measure

CHARACTERISTICS	APOM	FIM™+FAM
Construct measured	8 domains: Process skills (8 items), Communication skills (10 items), Life skills (13 items), Role performance (4 items), Balanced life style (3 items), Motivation (5 items), Self-esteem (7 items) and Affect (3 items).	2 domains: 13 Motor items and 8 Cognitive items
Conditions used in validation studies	Mental illness including schizophrenia, Mood disorders, Psychosis due to substance abuse, Post traumatic stress disorders, intellectual impairment and Personality disorders	Wide range of conditions including TBI, Stroke, Spinal cord injury, Multiple Sclerosis, Parkinson's Disease, Low back pain
Level of measurement	Ordinal scale, thresholds ordered for 18 category scale for all domains	Ordinal scale, thresholds disordered for a 7-category scale but ordered for a 4-category scale for motor items (Lundgren-Nilsson 2005)
Validity	Content, construct and criterion validity established	Vast number of validation studies over 30 years.
Reliability	Good inter-rater reliability but training in the use of the APOM is necessary Internal consistency is good with Cronbach alpha above 0.8 for all domains	Good inter-rater reliability, training is necessary in the use of the FIM™+FAM Internal consistency varies per condition, for TBI Cronbach alphas were above 0.78

Researchers are reminded by Merbitz, Morris and Grip about the misuse of ordinal scales in analyses.(81) Since the scales of the FIM™+FAM and APOM are on the ordinal scale of measurement, the limitations of analysis with ordinal data must be taken into account. Mathematical calculations cannot be done with ordinal scales since the distance between

points on the scale is not known. The points in the scale only represent a ranking e.g. a 2 on a scale is better than a score of 1 but is does not mean that 2 is double the score of 1. For this reason raw scores of a scale that is on an ordinal level of measurement may not be summed. However Grimby, Tennant and Tesio suggest that Rasch analysis be used to determine if an ordinal scale resembles the characteristics of and interval scale where mathematical calculations are possible.(82)

As reported earlier, the scale of the APOM has been subjected to Rasch analysis and the 18 categories of all the domains were ordered.(76) This investigation provides support that the raw scores of the APOM may be summed.

There is much debate about the use of a sum score for the FIM™+FAM. Lungren-Nilsson et al found that the 7-category scale when used with TBI and stroke patients was disordered for the motor items of the FIM™ but that all the motor items were ordered if the scale was collapsed to four categories.(80) Yet a factor analysis done by Turner-Stokes and Siegert showed that the construct of the UK FIM™+FAM is best presented in 4 distinct dimensions namely Physical, Psychosocial, Communication and Extended Activities of Everyday Living. These domains may be summed for a composite score of functional independence.(79)

In spite of controversy about the summed score of the FIM™+FAM, it continues to be a widely used outcome measure in rehabilitation. (24, 26, 55, 58)

3.7. Data Analysis

The data was analysed on a large number of scores as data was collected over a number of weeks for each participant. Therefore parametric statistics were used.

Researchers are reminded by Merbitz, Morris and Grip about the misuse of ordinal scales in analyses.(81) Since the scales of the FIM™+FAM and APOM are on the ordinal scale of measurement, the limitations of analysis with ordinal data must be taken into account. Mathematical calculations cannot be done with ordinal scales since the distance between points on the scale is not known. The points in the scale only represent a ranking e.g. a 2 on a scale is better than a score of 1 but is does not mean that 2 is double the score of 1.

Grimby, Tennant and Tesio suggest that Rasch analysis be used to determine if an ordinal scale resembles the characteristics of and interval scale where mathematical calculations are possible.(82)

Each objective of the study was analysed with a specific data analysis method, taking into account that the data for both the FIM™+FAM and APOM are on an ordinal level. Table 3.2 describes the methods.

Table 3.2: Methods of data analysis for each study objective

STUDY OBJECTIVE	UNIT OF ANALYSIS	METHOD OF DATA ANALYSIS
Comparison of responsiveness between APOM and FIM™+FAM	Standardised Response Mean (SRM) of domains of the APOM and Motor and Cognitive FIM™+FAM	Dependent t-test to test for significant difference between SRM as captured by APOM and FIM™+FAM
Trends in activity participation	SRM of domains of the APOM and Motor and Cognitive FIM™+FAM	Descriptive analysis using graphs.
Relevance of APOM to TBI	Raw scores of domains of the APOM and Motor and Cognitive FIM™+FAM	Pearson Correlation coefficients

To compare the responsiveness between the APOM and FIM™+FAM, the dependent t-test for paired samples was done to test if the null hypothesis should be rejected.

Responsiveness was calculated using the Standardised Response Mean (SRM). This statistic calculates the mean change of the sample, which is the final assessment score minus the baseline assessment score and divides it by the standard deviation of the changed scores. Middel discusses cut off points in this article on statistical significant change versus relevant or important change in health related research. These cut off points are as follows: trivial change as (ES<0.20); small change as (ES≥0.2≤0.50); moderate change as (ES 0.5<0.80) and large change as (ES≥0.80).(8)

Trends in activity participation were described with graphs. The graphs indicate which domains in the APOM showed more progress and which showed the least progress. The same was done for the FIM™+FAM.

Trends in activity participation related to specific independent variables were correlated e.g. length of stay, family support, Rancho los Amigos admission and discharge scores and age.

Relevance of the APOM for patients with TBI was tested by means of Pearson correlations. Correlations were done between the APOM domains and the cognitive and motor FIM™+FAM as well as the total FIM™+FAM. Since the FIM™+FAM appears to be a commonly used outcome measure in TBI, it was assumed that a high correlation between the APOM and FIM™+FAM could indicate that the APOM is relevant to be used in the TBI population. High correlations above 0.8 between each domain of the APOM and the cognitive items of the FIM™+FAM would indicate that the domain is relevant for TBI. Weaker correlations between the domains of the APOM and the motor items of the FIM™+FAM (below 0.7) would indicate that the APOM does not measure physical aspects of TBI. Correlations were also done between the domains and of the APOM and total FIM™+FAM. A high correlation above 0.8 would indicate relevance of the APOM to TBI since the FIM™+FAM is used in TBI. The raw scores were used to calculate the correlations.

3.7. Ethical Considerations

Ethical clearance for this study was received from the University of Witwatersrand (Clearance Certificate M130811) (Appendix E) Institutional approval was granted in writing By Mrs N. Strydom, the national rehabilitations standards manager of the healthcare group (Appendix F). In addition the rehabilitation facility practice manager, gave verbal consent for the study to be conducted.

All patients or next of kin (for those who were determined by the MDT to not be able to make an informed decision) admitted to the unit who were deemed appropriate as fulfilling the criteria of admission to the study were given an information letter with consent slip attached (Appendix E). This invited the patient to participate in the study. In

addition the researcher spoke to patients and their families about the nature and purpose of the research. Where English was not the first language, a member of the MDT translated into either Zulu or Xhosa which were the primary other languages of the sample.

Both the outcome measures used have an online data capturing programme, thus protecting the confidentiality of the participating patients as required. In research involving persons, every precaution to protect the privacy of the research subjects and confidentiality of their personal information needs to be undertaken (Helsinki Declaration).(83) This was done by assigning a number to the patients' computerised hospital number instead of their names. A list of the participating patients and their corresponding research numbers was kept safely and securely by the researcher.

Chapter 4 Results

4.1. Introduction

This chapter reports on results that have emerged from analysis of the raw data. The demographics of the sample are presented first. The responsiveness of the FIM™+FAM and the APOM are compared. Trends in activity participation as captured by the APOM are described by means of tables and graphs. The ability of the two instruments (APOM and FIM™+FAM) to detect real change in independent activity participation are presented and finally, the relevance of the APOM to patients with TBI are described.

4.2. Demographics of the sample

Of the 28 patients that were available for the study, data from 24 was used. Three patients were excluded as they had not been treated by a therapist trained in the use of the APOM. The fourth patient not included, was medically unstable and had repeated discharges and readmissions from the acute hospital setting to the rehabilitation unit within the overall length of stay.

The average length of stay in the rehabilitation unit for patients with TBI in this study was 51.91 days. The length of stays ranged from 9 to 118 days.

There were 17 males participating in the study and seven females. There was equal representation of males in the 18-30 age group and 51-60 age group. This is tabulated below.

Table 4.1: Demographic table showing males and females and the respective age ranges. (n=24)

		18-30	31-40	41-50	51-60	61-70	71-80	%
No of males	17	4	3	3	4	1	2	71
No females	7	1	0	2	2	2	0	29
Total	24	5	3	5	6	3	2	100

The largest number of TBIs in the study was as a result of MVAs followed by falls. (Table 2)

Table 4.2: Comparison of numbers of males and females with mechanism of Traumatic Brain Injury (n=24)

Gender	MVA	MBA	Assault	Falls	Pedestrian	Total
Male	8	3	1	3	2	17
Female	2	0	0	4	1	7
Total	10	3	1	7	3	24
%	42	12.5	4	29	12.5	100

As shown in table 4.3 below, in the older age group, TBI was as a result of falls. This is congruent with international trends.(84)

Table 4.3: Comparison of age ranges and mechanism of injury (n=24)

	18-30	31-40	41-50	51-60	61-70	71-80	Total	%
MVA	1	3	3	2	1	0	10	42
MBA	1	0	1	1	0	0	3	12.5
Falls	1	0	1	2	1	2	7	29
Pedestrian	2	0	0	0	1	0	3	12.5
Assault	0	0	0	1	0	0	1	4
Total	5	3	5	6	3	2	24	100

4.3 Comparison of responsiveness between Activity Participation Outcome Measure and the Functional Independent Measure™ and the Functional Assessment Measure

The standardised response means (SRM) was used to determine change in the APOM and the FIM™+FAM. This was calculated using the baseline assessment in the first week of treatment and the final assessment in the last week of treatment. The mean change was then divided by the standard deviation of the total scores. (Figure 1)

Middel's cut off points for significant change were used as the guide to interpret the size effect. The findings of this study show that the changes were well above this cut off point for the large category of ≥ 0.8.(8) Coster, Haley and Jette however reported that there is no gold standard for change after rehabilitation and that further investigation is needed to establish ideal change.(85)

The APOM showed a slightly higher average change than the FIM™+FAM but the dependent t-test (Table 6) indicated that the difference was not statistically significant (p=1.349).

The null hypothesis was that the APOM is no more responsive than the FIM™+FAM in demonstrating change. Based on the results the null hypotheses was accepted. It was accepted with a p-value of 1.349 (Table 4.4). Stastically there is no difference between the responsiveness of the APOM and FIM™+FAM based on total scores.

Table 4.4: The dependent t-Test between changes measured by the Activity Participation Outcome Measure and Functional Independence Measure™ and Functional Assessment Measure

	APOM Ave change	*FIM™ Ave change*
Mean	4.575	8.815
Variance	5.386	17.806
Observations	24	24
Pearson Correlation	0.950	
Hypothesized Mean Difference	0	
df	23	
t Stat	-9.706	
P(T<=t) two-tail	1.349	
t Critical two-tail	2.069	

4.4. Trends in changes of activity participation and independent functioning

The trends in changes of activity participation as measured by the APOM and level of independent functioning as measured by the FIM™+FAM are presented in figure 1.

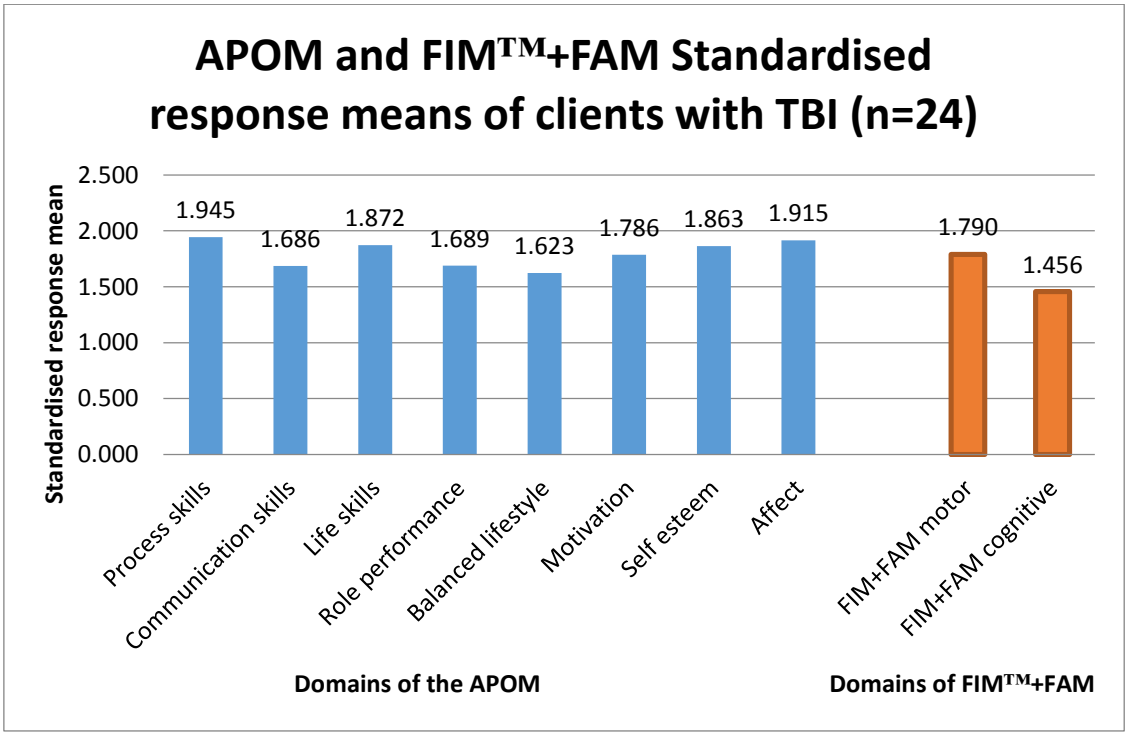


Fig 1: Activity Participation Outcome Measure and Functional Independence Measure and Functional Assessment Measure and standardised response means of clients with Traumatic Brain Injury (n=24)

The SRMs indicated positive changes from baseline to final assessment scores. In the APOM Process skills showed the largest change followed by Affect. Life skills and Self-esteem showed similar change. Balanced Lifestyle showed the smallest change.

In the FIM™+FAM the motor domain showed greater improvement than the cognitive domain. The cognitive domain showed the smallest change out of all domains of both outcome measures.

Trends were further described by means of correlations between dependent and independent variables. (Table 4.6)

The strongest positive correlation was between the changes in the APOM and the changes in the FIM™+FAM at 0.952. This correlation between the SRMs of the APOM and FIM™+FAM of 0.952 (Table 4.6) supports the acceptance of the null hypothesis. The results thus showed that the APOM is not statistically more responsive than the FIM™+FAM.

Other interesting correlations (above 0.7) were found between the Ranchos admission scores and baseline scores of both APOM and FIM™+FAM. The Ranchos final score correlated well with the APOM final score (0.888) and with the FIM™+FAM (0.725).

A moderate negative correlation of -0.582 was found between age group and length of stay which could indicate that the younger the person the longer the length of stay. However this must be interpreted with caution due to the small sample size and limited participants per age group.

Table 4.5: Correlations between dependent and independent variables

	Age group	*LOS*	*Ranchos Admission*	*Ranchos discharge*	*Family support*	*z score APOM change*	*z score FIM change*	*TOTAL AVERAGE APOM Baseline*	*TOTAL AVERAGE APOM Final*	*TOTAL AVERAGE FIM+FAM Baseline*
Age group	1									
LOS	-0.582	1								
Ranchos Admission	-0.107	-0.234	1							
Ranchos discharge	-0.341	0.140	0.461	1						
Family support	0.016	-0.040	-0.238	0.111	1					
z score APOM Change	-0.438	0.586	-0.172	0.561	0.180	1				
z score FIM change	-0.407	0.604	-0.110	0.582	0.149	**0.952**	1			
TOTAL AVERAGE APOM Baseline	0.151	-0.530	**0.770**	0.351	-0.057	-0.500	-0.418	1		
TOTAL AVERAGE APOM Final	-0.251	-0.023	0.658	**0.888**	0.103	0.394	0.437	0.598	1	
TOTAL AVERAGE FIM+FAM Baseline	0.055	-0.437	**0.816**	0.331	-0.350	-0.336	-0.302	**0.776**	0.512	1
TOTAL AVERAGE FIM+FAM Final	-0.275	0.167	0.542	**0.725**	-0.213	0.504	0.615	0.275	**0.754**	0.538

A moderate positive correlation of 0.604 and 0.586 was demonstrated respectively for FIM™+FAM and APOM change and length of stay. This may imply that a longer length of stay could result in better outcomes.

4.5. Relevance

The relevance of the use of the APOM in TBI neurological rehabilitation was investigated by means of Pearson's correlations. The raw scores of each domain of the APOM was correlated with the total score of the FIM™+FAM.

The APOM showed a strong correlation with the total score FIM™+FAM. The three lowest correlations namely Affect, Motivation and Role Performance are depicted in the scatter plots below and will be discussed in the following chapter.

Correlation of raw scores of the domains of the APOM showed good correlations above 0.7 (table 4.7).

Table 4.6. Correlations between the raw scores of the domains of the Activity Participation Outcome Measure and the domains of the Functional Independence Measure™and Functional Assessment Measure

	Motor FIM™+FAM	Cognitive FIM™+FAM	TOTAL FIM™+FAM
APOM Process	0.747	0.839	0.835
APOM Communication	0.675	0.840	0.789
APOM Lifeskills	0.755	0.822	0.833
APOM Role Performance	0.678	0.820	0.782
APOM Balanced Lifestyle	0.710	0.828	0.806
APOM Motivation	0.723	0.824	0.813
APOM Self-esteem	0.712	0.843	0.813
APOM Affect	0.686	0.823	0.789

The motor FIM™+FAM items correlated below 0.8 with the APOM domains. This was expected as the APOM domains do not include motor aspects. The cognitive items on the FIM™+FAM all correlated above 0.8 with the APOM domains. This was also not an

unexpected result as the APOM domains are easily associated with the cognitive items of the FIM™+FAM. The correlation between the total APOM and total FIM™+FAM is above 0.8 which supports the relevance of the APOM for the TBI population.

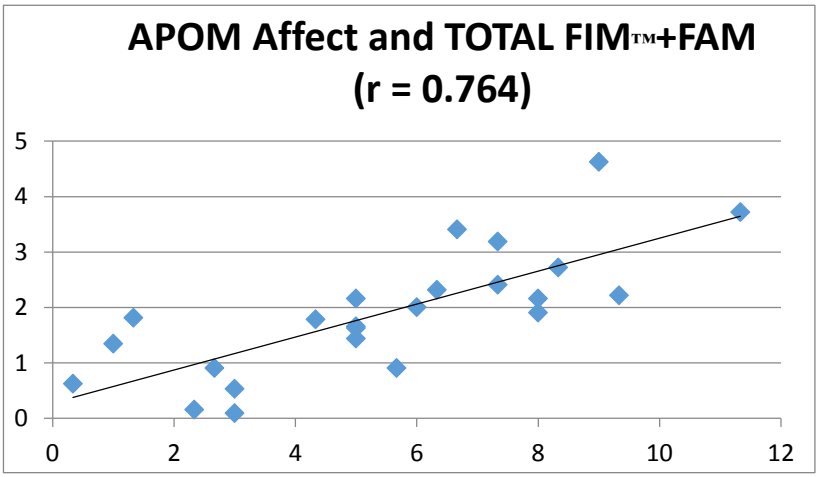


Figure 2: Correlation between Activity Particpation Outcome Measure Affect and Total Functional Independence Measure™ and Functional Assessment Measure

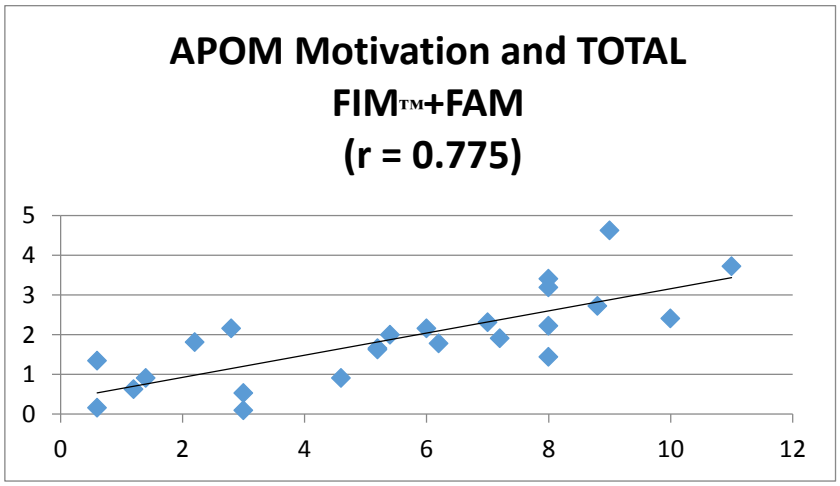


Figure 3. Correlation between Activity Participation Outcome Measure motivation and total Functional Independence Measure™ and Functional Assessment Measure (n=24)

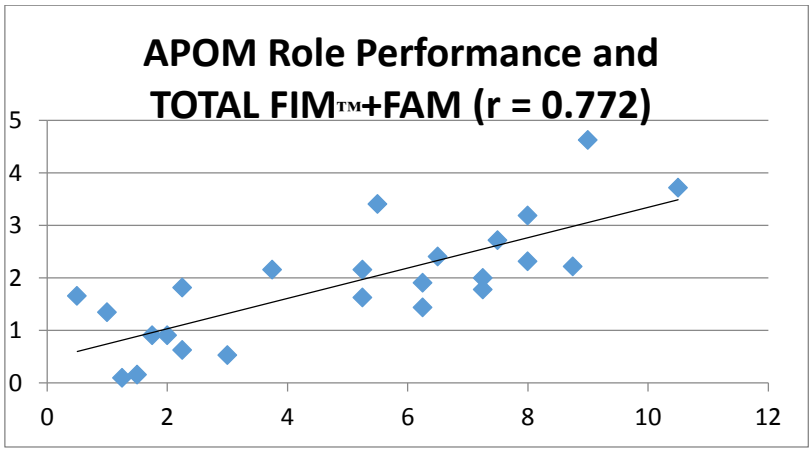


Fig 4. Correlation between Activity Participation Outcome Measure Role Performance and Total Functional Independence Measure and Functional Assessment Measure™+FAM(n=24)

4.6 Conclusion

The demographics of the sample and results of the three objectives of this research were reported in this chapter. The main findings were that there is no signficant difference between the responsiveness of the APOM and the FIM™+FAM when used in a population of patients with TBI. Both measures showed change in activity particiaption (as measured by the APOM) and an increase in independent functioning (as measured by the FIM™+FAM). Trends in activity participation showed a positive change in all domains of the APOM and FIM™+FAM. It appears that a longer stay may result in better outcomes for this sample but should be interpreted with caution as the statistical power with the sample of 24 was only 70%. The relevance of the APOM to the TBI population was good with a good correlation above 0.8 with the total FIM™+FAM.

Based on the results the null hypotheses was accepted. Stastically there is no difference between the responsiveness of the APOM and FIM™+FAM based on total scores.

Clinical implications of these findings are discsussed in the next chapter.

Chapter 5 Discussion

5.1. Introduction

This chapter describes the key findings of the study and pertinent findings from other studies. Limitations of the study are also presented as well as a summary of the clinical and research findings. The discussion follows the sequence of the research objectives where each objective and the clinical implications thereof are discussed. The chapter ends with the limitations of the study and recommendations for future research.

5.2. Demographics

Of the 28 patients with TBI admitted during the course of the year (September 2013-September 2014), all consented to participate in the study.They either gave verbal and written consent directly or a designated family member gave permission on their behalf. Data was analysed from 24 of the patients .

This number was below the recommended size of 28 for a confidence level of 95%. The confidence level drops to 70% with a sample of 24. This influences the power or reliability of the findings. All findings have to be interpreted with caution. Weekly recordings using the APOM and FIM™+FAM were done per patient, giving a total set of 176 observations. These multiple observations strengthened the reliability of the correlations done in terms of responsiveness and relevance of the APOM.

Data were not analysed from four patients, for the following reasons. Three of the patients were treated by therapists who had not been trained in the APOM and as a result, these patients only had FIM+FAM scores. One patient was physiologically unstable through his stay and had repeated discharges and readmissions to the acute medical setting. The patient was not able to execute tasks of basic self care without risk of developing stridor and compromising his breathing.

There were more males represented in the study than females. Only 30% of the sample were females. This is consistent with the findings of the IMPACT study in anlayisng demographics as prognosticators of outcome where 23% of the sample was female. (48)

In the researchers experience of 17 years working with the TBI population, this trend of more males than females is a typical occurrence. In the IMPACT study there was no statistical link between gender and a more favourable outcome.(48)

The greatest causes of injury in this sample were MVAs followed by falls. There was only one TBI as a result of assault which differs from the study performed at IALCH where assaults comprised the greatest mechanism of injury.(11) However in the 2014 study at Groote Schuur similar findings were found to this study, with MVAs being more common than assault.(37) This possibly could be because the study was conducted in a private facility where a different spectrum of patients was admitted versus those being admitted to IALCH.

Falls resulting in TBI were found more in the older patients' group which is consistent with literature.(48, 84)

There were no patient deaths during the study period, however one patient from the 71-80 yr age group died within one month of his discharge home from medical complications associated with his TBI.

5.3. Comparing responsiveness between the Activity Participation Outcomes Measure and the Functional Independence Measure™ and the Functional Assessment measure

The SRM was used to determine the change during and after rehabilitation as measured by the two outcome measures. It was anticipated by the researcher that the APOM would show the greater responsiveness of the two measures. Although the APOM showed a larger SRM than the FIM™+FAM (1.797 vs 1.623), it was not statistically significant. On the contrary there was a strong correlation (0.95) between the SRM of the APOM and the FIM™+FAM. This finding has a positive implication and could indicate that the two measures are measuring similar underlying constructs of activity participation and independent functioning.

Considering that the APOM was developed for the field of mental health specifically, it highlights that persons who have sustained a TBI can fall into the classification of people requiring mental health input. This could have possible funding implications for programmes run by mental health organisations e.g. Durban Mental Health Association.

In unpublished data, Casteleijn showed a greater responsiveness in determining change of occupational performance using the APOM in mental health users than that found in this study.(86) The patients in Casteleijn's data had primary psychiatric diagnoses. The results of this indicated highly significant changes in all domains with the highest score in Motivation and the lowest in Communication/Interaction Skills. In this research, on the use of the APOM in TBI, it was found that Process Skills showed the biggest change followed by Affect. The domains of Life skills and Self Esteem showed a similar change as the TBI sample, while the domain Balanced Lifestyle showed the smallest change of the APOM.

Process Skills are the cognitive and executive functions that one uses to perform a task. This includes the ability to plan a task, select and use tools and materials appropriately, to pace the actions required and to adapt one's performance when problems are encountered.(4) The literature has confirmed that the most common problems at one year post injury to be problem solving, memory, managing stress and emotional outbursts.(15) The domain of Affect showed the second biggest change. This domain incorporates repertoires of emotions, the control of emotions and mood.(4)

There are possible reasons for the great change noted in these areas. Firstly there is evidence in the literature that the brain is spontaneously recovering after trauma. The state of internal chaos, as described by Winkler in her chapter on TBI, begins to settle with this spontaneous recovery in an ordered external environment and appropriate input by the MDT.(15) Hence one would expect to see the measureable changes that were observed in this study, when using an outcome measure that is sufficiently responsive to demonstrate that change. The cognitive domain of the FIM™+FAM has been shown to be less responsive in demonstrating change and those findings from literature were demonstrated in this study too.(22)

The Balanced Lifestyle domain incorporates the following areas: time use, routines, habits and mix of occupations. It is understandable when looking at the acute neurological rehabilitation environment where a daily routine is provided and the focus is on reducing the patients' burden of care, that this domain would show the lowest

change. There is little opportunity for a patient to demonstrate a mix of occupations and independent use of time and routines.

In the FIM™+FAM the motor domain showed greater improvement than the cognitive. Overall, in all domains of both measures, the cognitive domain of the FIM™+FAM demonstrated the smallest change. This supports findings from other studies.(22)

The acceptance of the null hypotheses that there is no difference in responsiveness between the use of the FIM™+FAM and the APOM in demonstrating change in the acute phase of TBI neurological rehabilitation implies that either could be used successfully to indicate changes in activity participation which is the focus of occupational therapy and independent functioning which is the focus of other allied health professionals.(27)

5.4. Trends in changes after intervention

The trends that are to be discussed in the following paragraphs are based on the domains of the APOM and the Motor and Cognitive components of the FIM™+FAM (refer to Fig.1). Trends in length of stay, age groups of the patient population and the use of the Rancho Los Amigos scale in the neurological rehabilitation unit where the study occurred are discussed. Cost implications and time taken for the utilisation of the measures are also discussed.

Age and length of stay

A moderate negative correlation of -0.582 was found between age group and length of stay which could indicate that the younger the person the longer the length of stay. However this must be interpreted with caution due to the small sample size and limited participants per age group. An outlier in the study could have skewed this as one of the younger patients in the study was one of the more severely injured and this resulted in a longer length of stay of 118 days to achieve a safe discharge. The average length of stay for the group was 51.91 days. The length of stay is directly dependent on the funder and their policies around acute in-patient rehabilitation. Unfortunately this approach sometimes disregards patient progress.

Rancho Los Amigos Scale

In the neurological rehabilitation unit where the study was conducted, the Rancho Los Amigos scale is used as a rating method on admission to guide therapy intervention and give assistance to families on how to interact with their family member. A correlation of above 0.7 was found between the baseline scores of the FIM™+FAM, Rancho Los Amigos score and the APOM. This indicates that both outcome measures are able to indicate a Rancho Los Amigos score at baseline. For instance, the lower the score on the APOM or FIM™+FAM, the lower the Rancho scale will be. Using three instruments that point to one variable has cost implications. This is a huge issue in health care as resources are scarce and should be used responsibly.

The next section elaborates on the cost implications with the use of the APOM, FIM™+FAM and the Rancho Los Amigos scale.

Cost implications

The importance of this is a cost implication from both the use of the outcome measure as well as the time taken to score it. The FIM™+FAM and the APOM have a cost implication in order to use them, in addition to requiring training in their use which is also at a cost. For the South African scenario the cost implication of the APOM is far less than the FIM™+FAM due to the latter requiring payment in US dollars and this is influenced by the exchange rate. In addition the FIM™+FAM requires ongoing recertification of therapists every two years in order to maintain the licence, again at a cost per therapist in US dollars.

The APOM requires an initial training fee and then a monthly subscription in order to utilise the web-based facility. Once data is loaded onto the system, a descriptive report is generated which is helpful as a tool for communicating with families and employers. Both the FIM™+FAM and APOM generate a spider graph which can be shown to visually track the progress each time there is an entry. (See Appendices B+D)

The Rancho Los Amigo Scale has no cost attached to it. As mentioned in the literature review it offers a description of where the current level of functioning of the patient with TBI is at. It is easy to use and has the advantage of a family information sheet that can be

given to families with ideas of how to handle their loved ones at each level. This is found to be particularly useful with involved families. However it is difficult to use as a quantifier in measuring change for the benefit of funders.

Time

Time is a factor for allied health professionals when using an outcome measure.(87) The researcher found that once a therapist was trained in the APOM and familiar with its use, scoring a patient on a weekly basis took approximately ten minutes, no longer than is taken with the FIM™+FAM. Thus contrary to the findings of Trauer, Gill, Pedwell and Slattery time is not found to be a deterring factor in either of the outcome measures in this study.(87)

Length of stay (LOS)

A moderate positive correlation of 0,604 and 0.586 was demonstrated respectively for the FIM™+FAM and APOM change, and length of stay. The implication is that a longer stay could result in better outcomes. In a study by Hawkins reviewing outcomes and LOS, it was determined that using the FIM™ as the outcome measure at admission, discharge and one year follow ups, length of stay did not have a significant impact on outcome at one year. With a shorter length of stay, there was a greater burden of care placed on family on discharge and the need for community resources such as outpatient rehabilitation.(88) As discussed in the literature review, the focus of acute in-patient rehabilitation is the restoration of basic self-care tasks such as eating, grooming, dressing and bathing as well as basic functional mobility.(19) If these tasks are not achieved, a caregiver is required on discharge putting a burden on the family in terms of financial and personal resources.(89) In a resource poor country such as South Africa, accessing outpatient therapy is problematic.(90) In the ideal situation, patients presenting with a TBI should be able to receive inpatient neurological rehabilitation until their ability to manage their self-care tasks is achieved where possible, thereby reducing their burden of care on discharge home.

Family support

Family support as a variable was recorded with two options: “supportive and involved” or “minimally involved”. Statistically the correlations were low, between family involvement and outcome between the FIM™+FAM, APOM or the Rancho Los Amigos Scale. A possible reason for this in the study is the acute nature of the setting. The patients had come from the acute medical setting directly to the acute neurological rehabilitation setting. Families had been through emotional trauma during those early acute medical days with the survival of their family member being the primary concern. It is often perceived by the family in the acute setting that if their family member can leave walking then all will be well. In 51.9 days it is very difficult for anybody to grasp the significance of the impact that TBI will have on their lives as a family, particularly the cognitive neurological sequelae.

Over the years of the functioning of the rehabilitation unit, it has been observed that those TBI patients who are discharged home at an optimal level of functioning, who have involved families, and who are financially stable, tend to survive with fewer complications. This was not the scope of the research, but it is still notable that a reduction of burden of care at time of discharge by improving the level of participation in basic ADLs and IADLs, leads to an improved overall ability of families’ ability to cope. This then leads to a better long term prognosis for the patient.(89)

5.5 Relevance of the Activity Participation Outcome Measure in Traumatic Brain Injury

The correlations of the raw scores showed a good correlation between the total APOM and FIM™+FAM scores. This was from a statistical point of view. From a clinical point of view, the APOM provided greater insight into patients’ activity participation in occupational performance capabilities than the FIM™FAM. The items of the domains provided a clearer picture in terms of Motivation, Affect, and Self-esteem. These are known areas of difficulty in the TBI population and were not identified in the FIM™+FAM. The FIM™+FAM on the other hand covered the motor aspects which the APOM did not cover. The Lifeskills domain area was of least clinical use in the APOM. It was unable to

show the physical changes that occur on a participation level that the FIM™+FAM could show. An example is with the FIM™+FAM self-care is divided into dressing, bathing, washing, grooming while the APOM has one item in the Lifeskills domain covering all aspects of self-care.

In the APOM the prevocational skills item was of more use than the vocational skills item, with its incorporation of personal and social presentation skills required and aspects of work competency. In the vocational skills item, which involved skill and knowledge in a specific field, work speed and physical and psychological endurance, it was noted that splinter skills in TBI patients who have been working in their field for many years were often preserved. Partial knowledge was often retained, but the work speed and endurance were not and in the acute phase, these did not show the dramatic changes that would allow the patient to return to their work environments immediately after discharge.

The researcher and colleagues trained in the APOM, believed it to be beneficial in guiding their therapy goals because it enabled them to focus on activity participation levels instead of being impairment focused. In addition they felt that the APOM was able to guide their feedback to the families of the patients. They believed that they were able to be more descriptive in what they said, allowing for better education of the family as to the nature of TBI.

While statistically there was no difference in the responsiveness of the two outcome measures studied, the APOM was more useful to track changes on a weekly basis. The scale of the APOM is based on the levels of Creative Ability, where each level is subdivided into stages. These stages as described as a progression from therapist directed, to patient directed and then into a transitional stage to the next level. When a patient was thought to be stagnating in their progress, by reviewing at what stage they were on in each level, this helped the therapists to demonstrate change to the funders descriptively in the weekly reports. Casteleijn investigated the validity of these levels to determine if they indeed represent increasing amounts of ability and found that the scale follows a linear or hierarchical pattern. Threshold ordering of the Rasch analysis was used and supported the validity of the levels.(76) Unfortunately the results of the APOM were

not used by the funders during this research as the purpose of the research was to explore if the APOM would be relevant to the TBI setting and not yet to influence funding.

The question has to be asked if the APOM could be used by occupational therapists in a MDT environment where its underlying theoretical tenets are not known or understood by other disciplines of the team. It is believed that the APOM can be used successfully by occupational therapists when reporting change to the MDT. Information gathered from other team members can help the occupational therapist determine what level the patient should be at. Although MDT members may not use the APOM or fully understand the clinical implication of each level, the descriptors in the APOM are self-explanatory which any MDT member can understand. A report with these descriptors is generated for each patient and accessible to other MDT members. In addition, feedback in occupational performance as described by the APOM can be shared with team members in order for them to assist with setting discipline specific goals.

TBI patients in the acute stage display a wide variety of impairments and there is little heterogeneity amongst them. For this reason the APOM would be of better use for those patients who are colloquially described as being "walkie-talkies". These are the patients who are automatically walking and talking but cannot make decisions about their care, follow a routine, participate in basic problem solving, and display dysexecutive functioning. Their activity participation is low, and they are often deceptive in their presentation. Families and therapists initially think that they are at a higher level of functioning than they actually are. The APOM with its underlying theoretical principles of Creative Ability is able to describe and quantify the levels of motivation and subsequent action. This will give a clearer picture of those kinds of patients and help to quantify their true level of activity participation in occupational performance. This is not able to be achieved as successfully with the FIM™+FAM, as the patients will have high ratings for the physical components and communicative scores. Their overall rating will indicate that they are functional but will not show the significance of their cognitive impairment on occupational performance.

To illustrate this, one can take a task of dressing the upper body. A patient with a TBI scores at maximum assist (score of 2) on the FIM™+FAM despite having the physical

capability to perform the task. There are no difficulties on the impairment level such as with range of motion, muscle strength or motor planning. The occupational therapist determines that the patient has a low level of motivation which is the underlying cause of the low score on the FIM™+FAM. There is no category for motivation on the FIM™+FAM, thus the therapist writes about this in the descriptive report as being a problem. It would be of great benefit to the patient and the funder if the therapist each week could give a valid numerical score to the level of motivation that is affecting participation. In this way the funder could see that change was occurring that would have an ultimate effect on dressing upper body.

The APOM is a measure that has demonstrated its usefulness in capturing TBI patients' level of occupational functioning in the acute stages of neurological rehabilitation. In addition it helped in goal setting and qualifying at what stage of participation the patient was, whether they were taking greater responsibility for an action or still requiring therapist direction for the task.

The use of the APOM in a MDT has its value. Use of more than one outcome measure is not justified financially. The lack of a measure of physical components in the APOM makes it a difficult measure to be the only one to use in an environment where there is a high physical burden of care in patients. However, it could be used in an environment where the physical impairments of a patient are quantified using impairment based scales such as the Berg Balance, Modified Ashworth scale for Spasticity, and Timed Up and Go Walking test. The value of the APOM would be that it would give a holistic picture of functioning that the occupational therapist could score with supplemental information from the rest of the team. The impairment based scales require no license in order to use, thus there are no additional costs incurred beyond the monthly administrative fee of use of the APOM.

5.6 Use of outcome-measures on a weekly basis

During the literature review no outcome measure reviewed was designed to be utilised on a weekly basis but on admission and discharge with a possible third score for longer length of stays. The responsiveness of outcome measures is compromised when used on a weekly basis when it has not been designed for that. The current practise of using the

FIM™+FAM on a weekly basis is a funder requirement. This may have a significant impact on treatment and goal setting. There is a risk for therapists to focus treatment on the outcome measure, in order to appease the funders, rather than patient driven goals. This can have significant ethical implications on therapists' autonomy to practise as Independent Practitioners, as well as on appropriate patient health care. Although the APOM has not being designed to be used on a weekly basis, it was found that because of the larger number of increments available for scoring, change was able to be seen realistically and legitimately.

Despite the under-represented sample, all of the objectives of the study were achieved. Statistically the power of the results may be compromised but many clinical implications were observed by comparing the APOM and FIM™+FAM in a population with TBI.

5.7 Limitations of the study

The study had a low number of participants. Despite the power sample being calculated at 28 based on annual TBI numbers in the unit, a small number of participants leads to an inflated SRM, thus one has to be cautious in interpreting the results.(91)

The sample was taken from only one unit. The fact that there is only one acute private neurological rehabilitation unit in the province restricted access to a possible larger number of patients.

In addition, there were only two trained occupational therapists in the unit that could utilise the APOM with their patients. Despite attempts made to direct all TBI patients admitted to those trained therapists, it was not always practically possible.

The study was constrained by a self-imposed time limit of 12 months for data collection. This was in order to meet the requirements of completing the degree for which this research was intended within the appropriate time frame. Possibly extending the data collection over a two year period would yield results that could be viewed with greater statistical power.

5.8 Recommendations for future study

From a practical point, establishing an Excel data capturing sheet at the beginning, would have been of benefit and saved time. Despite the APOM and FIM™+FAM having their own online databases, it was still required that this information be transferred onto a spreadsheet for analysis.

Ongoing data using the APOM should be collected as part of routine measurement of all TBI patients within the acute neurological rehabilitation setting. This then will allow for access over a longer period of time to obtain data, which would allow for increased power in future studies.

It would be of benefit to follow TBI patients into the community and re-evaluate at three months, six months and then annually post discharge, to determine their level of activity participation in a variety of settings. Follow-up studies are difficult particularly with a diverse population group such as in South Africa. Resources also need to be allocated for such reviews and the cost implications of such are often prohibitive.

5.9 Conclusion

Key findings from the study were discussed with reference to pertinent other research. The relevance of the APOM in TBI was discussed and the benefits of its use in an acute neurological rehabilitation setting within a MDT. Limitations of this research was discussed as well as recommendations for future research.

Chapter 6 Conclusion

The final chapter of this research report aims to give an overview of the research undertaken as well as comment on the use of outcome measures in general in rehabilitation.

The research was undertaken in an acute private healthcare neurological rehabilitation setting where the focus is primarily on patients with neurological diagnoses. Patients with TBI are admitted once deemed medically stable and undergo daily intervention from a MDT. The use of the FIM™+FAM is the outcome measure of choice by the healthcare company.

Weekly feedback is sent to the funders' in the form of a progress report together with the scores of the outcome measure used. Updates around length of stay are then given (by the funder) based on the progress as well as determined by the funders' policies for inpatient rehabilitation.

The APOM was chosen as an outcome measure that could be compared to the FIM™+FAM.

The results showed a strong correlation between the APOM and the total score FIM+FAM. There was no significant difference between the responsiveness of the APOM and the FIM+FAM when used in the TBI population. In addition the relevance of the use of the APOM in the TBI population was good.

Outcome measures are mandatory in neurological rehabilitation and should not be viewed as "necessary evils" by clinicians. The use of an appropriate outcome measure can provide valuable input in the acute rehabilitative phase of recovery post TBI. Reviewing the literature and personal use of a commonly used outcome measure (FIM™+FAM) has shown the researcher that all have limitations. The choice of which measure to use is determined by its cost effectiveness (time and licencing costs), what information is needed or wanted of the measure and what the results would be used for. In addition, in the South African context, major funders of healthcare have a strong influence in what outcome measures are used. This is not always based on current

science. Use of more than one outcome measure by a specific profession is an unjustifiable cost in any unit.

Instruments that measure activity participation are important in assessing TBI neurological rehabilitation outcomes. The use of the APOM in tracking change in TBI in the acute neurological rehabilitation phase has been demonstrated successfully in this study. The inclusion of impairment based assessment tools to track physical changes during the inpatient period would be of benefit and supplement the use of the APOM as a primary outcome measure in a MDT.

Outcome measures in TBI are moving towards measuring quality of life and activity participation. As presented in the literature review, Stiers determined that an increase in activity participation levels correlated with an increase in quality of life.(61) By measuring activity participation levels the APOM fits in with this current move towards focusing on quality of life and is recommended to be used in the acute neurological rehabilitation setting.

This study has demonstrated that with the APOM, South African occupational therapists have a measure that can track activity participation in TBI patients in the acute phase of neurological rehabilitation. This will allow occupational therapists to have greater input into the treatment of the patient and adds to the professional integrity of the discipline.

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Appendices

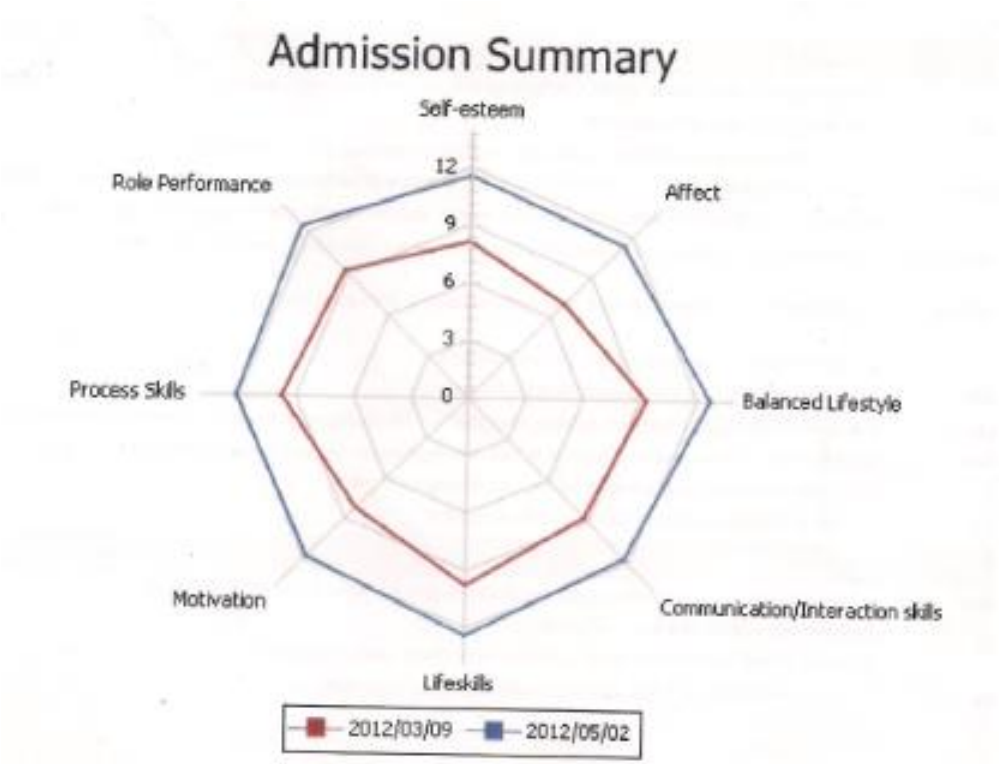
Appendix A APOM SCORING SHEET

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	

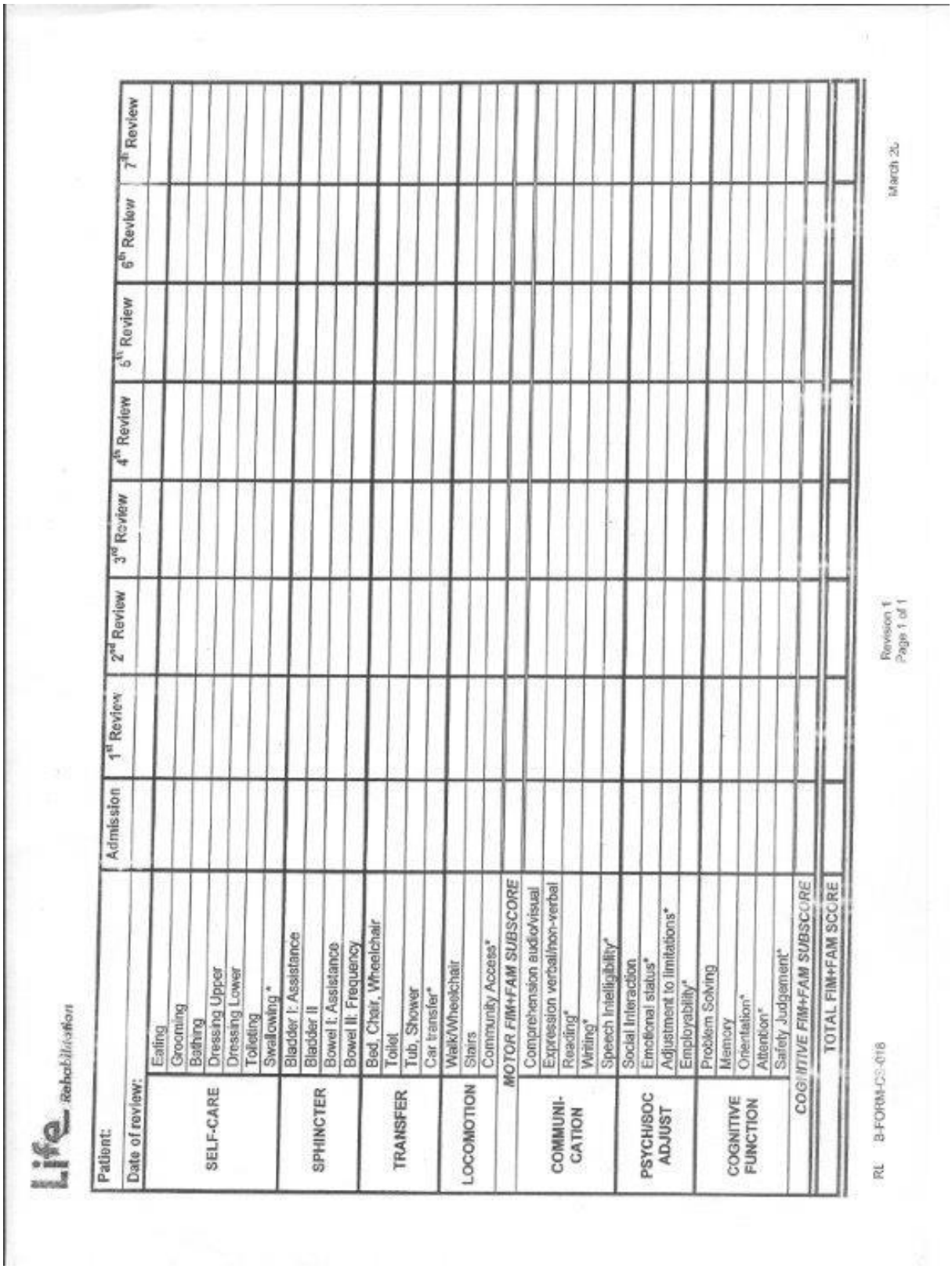
Lifeskills	
Personal care, hygiene, grooming	
Personal safety	
Care of medication	
Use of transport	
Domestic skills	
Child care skills	
Money management, budgeting skills	
Assertiveness	
Stress management	
Conflict management	
Problem solving skills	
Pre-vocational skills	
Vocational skills	
Average	
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. Spidergraph of APOM (Example)



Appendix C FIM+FAM SCORING SHEET

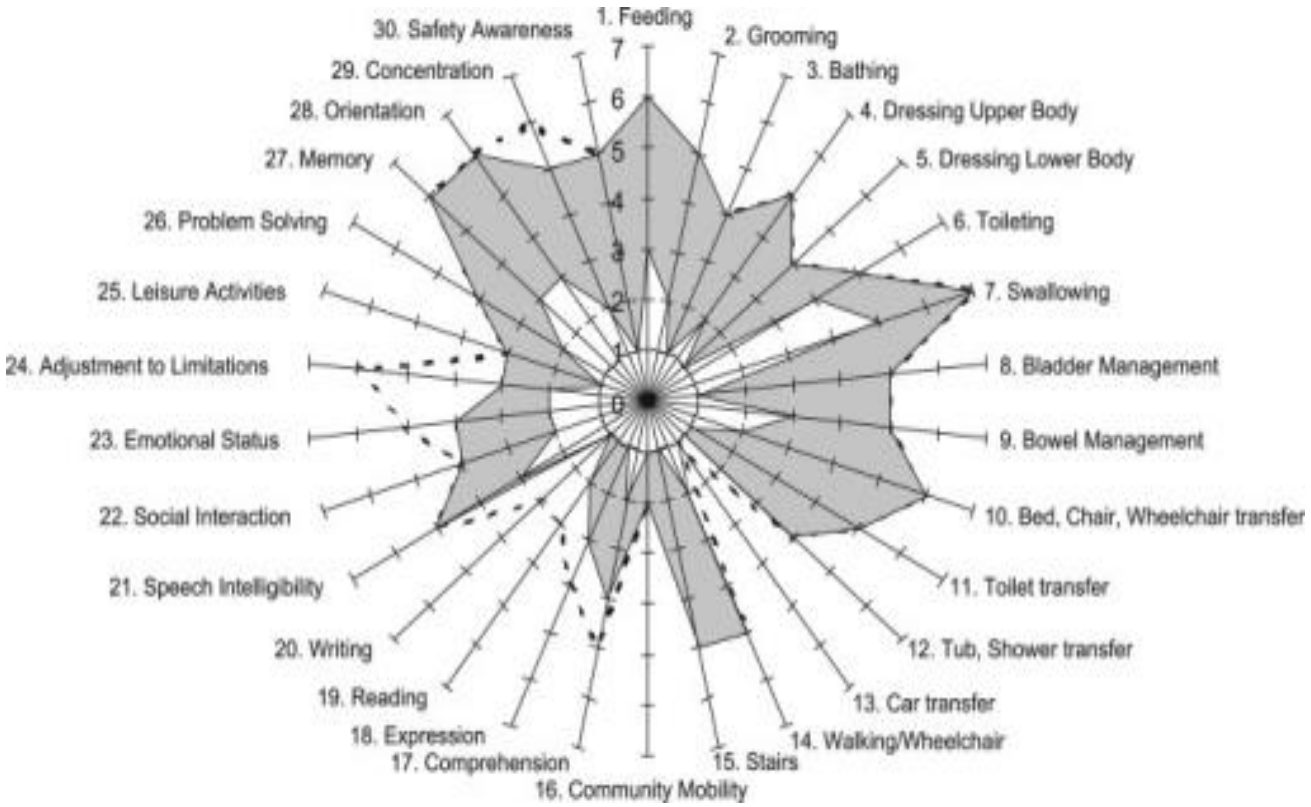


life Rehabilitation

Patient:		Admission	1st Review	2nd Review	3rd Review	4th Review	5th Review	6th Review	7th Review
Date of review:									
SELF-CARE	Eating								
	Grooming								
	Bathing								
	Dressing Upper								
	Dressing Lower								
	Toileting								
SPHINCTER	Swallowing *								
	Bladder I: Assistance								
	Bladder II								
	Bowel I: Assistance								
	Bowel II: Frequency								
TRANSFER	Bed, Chair, Wheelchair								
	Toilet								
	Tub, Shower								
	Car transfer*								
LOCOMOTION	Walk/Wheelchair								
	Stairs								
	Community Access*								
	MOTOR FIM+FAM SUBSCORE								
COMMUNI-CATION	Comprehension auditory/visual								
	Expression verbal/non-verbal								
	Reading*								
	Writing*								
	Speech Intelligibility*								
PSYCH/SOC ADJUST	Social Interaction								
	Emotional status*								
	Adjustment to limitations*								
	Employability*								
COGNITIVE FUNCTION	Problem Solving								
	Memory								
	Orientation*								
	Attention*								
	Safety Judgement*								
	COGNITIVE FIM+FAM SUBSCORE								
	TOTAL FIM+FAM SCORE								

RL B-FORM-CS-016 Revision 1 Page 1 of 1 March 20

Appendix D Spidergraph of FIM+FAM (example)



Appendix E: Ethical Clearance Certificate

R14/49 Mrs Alison Louise Camp

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130811

NAME: (Principal Investigator)	Mrs Alison Louise Camp
DEPARTMENT:	Department of Occupational Therapy Entabeni Rehabilitation, Entabeni, Durban, KZN
PROJECT TITLE:	A Comparison of the Responsiveness of Independent Activity Participation Outcome Measures in Patients with Traumatic Brain in an Acute Rehabilitation Setting
DATE CONSIDERED:	30/08/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Pat de Witt
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	07/10/2013

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 Secretary in Room 10004, 10th floor, Senate House, University.
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.**

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix F: Institutional approval letter

Life Rehabilitation

National Rehabilitation office
Oxford Manor, 21 Chaplin Road, Illovo, 2196
Private Bag X13, Northlands, 2116, South Africa
Telephone +27 11 219 9620
Facsimile +27 86 686 0441
www.rehab.co.za

22 May 2013

Ms Alison Camp

Request for permission to conduct research

Dear Alison

Many thanks for the request for permission to conduct research at our Life Entabeni Rehabilitation Unit, Durban on the topic: ***The use of the APOM as a rating scale for patients with traumatic brain injury in the acute rehab setting***

Life Rehabilitation supports the development of the field of rehabilitation through evidence-based research and we have a number of ongoing research projects in our units.

I hereby grant **provisional** permission to you to access the Life Entabeni Rehabilitation Unit in order to conduct your research.

As we value patient confidentiality and their right to choose, permission is granted under the following conditions:

- Ethical clearance from the University of the Witwatersrand
- Obtaining written permission from patients to participate in the study. If a patient is in any way unable to provide consent, the appropriate family member must participate in the decision-making process
- No patient may be identified, either by name or by the unit where the patient received his/her rehabilitation.
- Access to patient documentation must be controlled and supervised
- The data gathered may only be used for the purpose of the research no information obtained in our units may be used by third parties

Access to the unit is dependent upon permission by the relevant managers to limit disruption to the unit routine and patients' rehabilitation programmes. Please liaise with the Rehabilitation Practice Manager, Ms Sierra Mwangalawa.

Please provide a copy of ethical clearance for our records once received. I wish you success with your research, and look forward to the results. We would appreciate a copy of your research upon completion.

Sincerely,

Nina Strydom
Support Specialist
Clinical Products
Life Healthcare
Tel: +27 31 311 7912
Fax: +27 866781450
Mobile: +27 84 555 1281
Email: nina.strydom@lifehealthcare.co.za
Website: www.lifehealthcare.co.za

Appendix G: Information letter and consent slip

Information Sheet – Family Member

A comparison of the responsiveness of independent activity participation outcome measures in patients with traumatic brain injury in an acute rehabilitation setting

Hello,

I, Alison Camp am completing my master's degree in Occupational Therapy (Msc.OT) at the University of the Witwatersrand. As part of the degree I wish to study the outcomes measures we use with patients in the rehabilitation unit to assess their progress after a traumatic head injury. I wish to establish how well these outcome measures assess change in every day function of patients with traumatic brain injury which will help us judge the effectiveness of the treatment in the unit.

In the rehab unit, each week your family member will be scored using an outcome measure called the FIM+FAM. This is an outcomes measure that gives an indication of how well they are doing. This information is then sent to their medical aid/COID in their weekly progress report.

I wish to investigate an additional outcomes measure called the APOM (Activity Participation Outcomes Measure) and to compare the scores of each to see which one is more sensitive to change. The APOM will be scored at the same time as the FIM+FAM; on admission, weekly, on discharge and at three months after discharge.

I am inviting your family member who has had a traumatic brain injury to take part in the study. I am asking that I may record their FIM+FAM scores. These assessments are routine carried out on admission, weekly and on discharge and on follow up visits. I am requesting that you give permission for a second assessment, the Activity Participation Outcomes Measure to be completed on your family member while they are involved in an activity during your normal therapy sessions. This simply means that I will watch them complete activities and comment on how they do them. These assessments will be carried out just after admission, weekly, on discharge and three months after discharge on a follow up visit.

All the information collected will be confidential and only codes will be used on the data sheets, no names. Only I, the researcher will have access to any identifying information which will be kept separate locked in my office.

If you do not wish to give permission or your family member to take part in the study or wish to withdraw your permission for them to participate at any time this will not affect their therapy in any way. This study is completely voluntary and carries no penalty of any sort if you do not wish them to participate.

Life Rehabilitation has given me permission and the University of Witwatersrand have given me ethical clearance for the research project.

If you have any questions about the research during your family member's length of stay or afterwards, I will be happy to discuss them with you. For further enquiries or information with

regards to my research, please do not hesitate to contact me on 031-7623481 or the following e-mail address: alcamp1970@gmail.com

Should there be any ethical queries about the research please feel free to contact the Human Research Ethics Committee (HREC) Chairman Prof P Cleaton-Jones at 011 7171234 or anisa.keshav@wits.ac.za for reporting of complaints / problems
Please could you fill in the acceptance slip at the bottom of this paper about participating in this research project and return it to me.

Yours sincerely

Alison Camp (B.OT)

Occupational Therapist

Informed Consent Form

I, _____ (agree to allow my family member)

_____ to participate in this research project entitled **A comparison of the responsiveness of independent activity participation outcome measures in patients with traumatic brain injury in an acute rehabilitation setting**

. I understand that at any stage of the rehabilitation process I may withdraw permission for their participation and that this will have no impact on the therapy that I receive during their stay in the rehabilitation unit.

Signature: _____

Date _____