

https://dspace.org/

Content validity of the modified barthel index for stroke patients in South Africa

Breytenbach, Fiona

2016-10-12
http://hdl.handle.net/10539/21178

Downloaded from a DSpace repository. https://dspace.org/



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

CONTENT VALIDITY OF THE MODIFIED BARTHEL INDEX FOR STROKE PATIENTS IN SOUTH AFRICA

Fiona Breytenbach

A research report submitted to the Faculty of Health Sciences, School of Therapeutic Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of
Master of Science in Occupational Therapy (Neurosciences)

February 2016

DECLARATION

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

_____

Fiona Colleen Breytenbach

_____ day of _____, 2016.

PLAGARISM DECLARATION

Postgraduate Office, Faculty of Health Sciences
Wits Medical School, 7 York Road, PARKTOWN, 2193, Johannesburg • Tel: (011) 717 2745 • Fax: (011) 717 2119 • e-mail: healthpg@health.wits.ac.za

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I _____ (Student number: _____) am a student registered for the degree of _____ in the academic year _____.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this in not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature: _____ Date: _____

PRESENTATIONS & PUBLICATIONS ARISING FROM THE STUDY

Gauteng Department of Health. The Content Validity of the Modified Barthel Index in Stroke Patients in South Africa. OT Expo, Chris Hani Baragwanath Academic Hospital, 2015.

ABSTRACT

Background: The Barthel Index is considered the global golden standard for assessing of one's performance in self-care tasks, but little research has been performed on the integrity of this outcome measure for the South African stroke population.

Aim: The study aimed to determine whether the content validity of the Modified Barthel Index is adequate in assessing the ADL functioning of stroke patients in South Africa.

Research design: Mixed methods design using the nominal group technique

Methods: Four nominal group technique groups were held consisting of three to six participants per group. The study sample consisted of occupational therapists (n=11) and physiotherapists (n=4) with four or more years working experience (mean=13.7 years) in the field of adult neurorehabilitation in South Africa. Each group was presented with five questions based on the Table of Specifications methodology to analyse the content validity of the Modified Barthel Index. Data analysis followed Van Breda's steps to analysing multi-group nominal group technique data to establish themes arising from each question and were presented according to final rank scores.

Results: The themes receiving the highest rank score for each of the five questions concluded that the Modified Barthel Index should (i) be designed for use by therapists and nurses, (ii) remain in English, (iii) be re-worded to be clear and understandable, (iv) include all aspects of functional mobility, and (v) should accommodate for the effect accessibility barriers have on daily functioning.

Conclusion: The Modified Barthel Index requires revision to improve its content validity for the South African stroke population. This study provides recommendations for the standardization of the tool.

To my patients,
who continue to intrigue and inspire me.

ACKNOWLEGEMENTS

I would like to acknowledge the following people for their contributions:

- Mrs Juliana Freeme, my research supervisor – thank you for your continued guidance, help, and most importantly your encouragement and belief in me.
- The University of the Witwatersrand Occupational Therapy Department, Steve Biko Academic Hospital Occupational Therapy Department and Muelmed Rehabilitation Centre for allowing me to use their premises.
- My team at Kalafong Hospital, thank you to Riana Louw for always making my research a priority and Megan Roberts for your inspiration and support when I needed it the most.
- My team at Chris Hani Baragwanath Academic Hospital; Karessa Govender, Amy Volker, Tiffany Fairburn, Dani-Lee McMillan, Natalie Fernandes, Zukiswa Msengana - thank you for your patience and always fitting me into your busy schedules.
- Chantelle Pandelaere, for all your efforts in proof reading this report
- To all the participants in the study – thank you for attending and providing me with such valuable insights.
- Jeremy Breytenbach, my husband, for your support, prayers, encouragement and all the cups of tea.
- Thank you to my family for financial and emotional support throughout my undergraduate and postgraduate degrees – I would not have made it this far without you!

TABLE OF CONTENTS

DECLARATION i

PLAGARISM DECLARATION ii

PRESENTATIONS & PUBLICATIONS ARISING FROM THE STUDY iii

ABSTRACT iv

DEDICATION v

ACKNOWLEGEMENTS vi

TABLE OF CONTENTS vii

LIST OF FIGURES xi

LIST OF TABLES xiii

LIST OF ABBREVIATIONS xv

CHAPTER 1 1

1.1. Introduction to the Study 1

1.2. Statement of the Problem 2

1.3. Purpose of the Study 3

1.4. Research Question 3

1.5. Aim of the Study 4

1.6. Objectives 4

1.6.1. Objective 1 4

1.6.2. Objective 2 4

1.6.3. Objective 3 4

1.7. Justification of the Study 4

CHAPTER 2 6

2.1. Introduction to the Literature Review 6

2.2. Stroke 6

2.3. Stroke Rehabilitation 7

2.4. What are Activities of Daily Living? 8

2.4.1. Activities of Daily Living as defined by the Occupational Therapy Practice Framework and International Classification of Functioning, Disability and Health 8

2.5. An Activities of Daily Living Outcome Measure: The Barthel Index and Modified Barthel Index 11

2.5.1. Introduction to the Barthel Index 11
2.5.2. Development and versions of the Barthel Index 11
2.5.3. The Modified Barthel Index and its suitability for the South African context 12
2.5.4. Language of the Modified Barthel Index for the South African context . 12
2.6. Practice Framework Aspects of Activities of Daily Living in a South African Context 13
2.6.1. Bathing, showering 14
2.6.2. Toileting and toilet hygiene 15
2.6.3. Dressing 20
2.6.4. Swallowing/Eating 22
2.6.5. Feeding 23
2.6.6. Functional mobility 25
2.6.7. Personal device care 28
2.6.8. Personal hygiene and grooming 29
2.6.9. Sexual activity 31
2.6.10. Summary: Important differences between the Occupational Therapy Practice Framework and International Classification of Functioning, Disability and Health domains of Activities of Daily Living compared to the Modified Barthel Index 33
2.7. Psychometric Properties of the Barthel Index and its versions 37
2.7.1. Reliability 37
2.7.2. Validity 37
2.8. Conclusion of the literature review 44
CHAPTER 3 45
3.1. Introduction 45
3.2. Research design 45
3.2.1. An Outline to Analysing Content Validity 45
3.3. Study Population and Sample 51
3.3.1. Defining the jury: Study population 51
3.3.2. Defining the jury: Study sample 51
3.4. Research Measurement 53
3.4.1. Measuring instruments 53
3.5. Research Procedure 56
3.6. Data Analysis 58
3.6.1. Demographic questionnaire 58

3.6.2. Analysing multi-group nominal group technique data to establish content validity 59
3.7. Ethical Considerations 62
3.9. Summary 63
CHAPTER 4 64
4.1. Introduction to the Results 64
4.2. Demographics of Subject 64
4.2.1. Participants: Occupational therapists and physiotherapists 64
4.2.2. Universities where participants obtained their undergraduate degrees 65
4.2.3. Years of experience 65
4.2.4. Undergraduate training in the Barthel Index 66
4.2.5. Experience in administering the Barthel Index 67
4.3. Nominal Group Results 67
4.3.1. How to interpret results 67
4.3.2. Question 1: Who should administer the Modified Barthel Index? 68
4.3.3. Question 2: What language should the Modified Barthel Index be in? . 70
4.3.4. Question 3: How can we rephrase the Modified Barthel Index to make it more clear and understandable? 72
4.3.5. Question 4: Compare the Practice Framework to the Modified Barthel Index. Are there any items of the Modified Barthel Index you would include/exclude? 78
4.3.6. Question 5: How does South African activities of daily living differ from western activities of daily living? 82
4.4. Conclusion 86
CHAPTER 5 87
5.1. Introduction 87
5.2. Demographics of subjects 87
5.3. Objective 1: Are all Activities of Daily Living items included in the Modified Barthel Index according to current Activities of Daily Living theories and frameworks? 89
5.4. Objective 2: Is the content of the Modified Barthel Index appropriate for the South African population? 92
5.4.1. Appropriateness of the directions for the instrument 92
5.4.2. Content areas covered 93
5.4.3. Instrument items 95
5.4.4. Opportunity for revision of items 97

5.4.5. Opportunity to recommend deleting an item 97
5.4.6. Opportunity to add additional items to the instrument 98
5.4.7. Opportunity for additional comments 98
5.5. Evaluation of the Study 100
2.8.18 100
5.5.1. Limitations of the study 100
5.5.2. Recommendations for future studies 100
5.6. Conclusion 101
CHAPTER 6 102
6.1. Objective 3: Recommendations for adjustments to the Modified Barthel Index for the standardization of the tool for the South African population 102
REFERENCES 104
APPENDIX A 113
APPENDIX B 116
APPENDIX C 117
APPENDIX D 118
APPENDIX E 119
APPENDIX F 121
APPENDIX G 122
APPENDIX H 123

LIST OF FIGURES

Figure 2.1. Self-care domain as defined in the International Classification of Functioning, Disability and Health 8

Figure 2.2. Activities of Daily Living as defined in the Occupational Therapy Practice Framework (3rd edition) 10

Figure 3.1. Voting card 55

Figure 4.1. Professions of study participants (n=15) 64

Figure 4.2. Universities where participants obtained their undergraduate degrees (n=15) 65

Figure 4.4. Number of years of working experience in the field of neurorehabilitation (mean = 10.1 years) 66

Figure 4.3. Number of years of working experience as a therapist (mean = 13.7 years) 66

Figure 4.5. Percentage of participants who were trained to use the Barthel Index on an undergraduate level (n=15) 66

Figure 4.6. Percentage of participants that have administered the Barthel Index (n=15) 67

Figure 4.7. Themes arising from Question 1: 'Who should administer the Modified Barthel Index?', ordered according to final rank 69

Figure 4.8. Themes arising from Question 2: 'What language should the Modified Barthel Index be in?', ordered according to final rank 72

Figure 4.9. Themes arising from Question 3: 'How can we rephrase the Modified Barthel Index to make it more clear/understandable?', ordered according to final rank 77

Figure 4.10. Themes arising from Question 4: ‘Are there any items of the Modified Barthel Index you would include/exclude?’, ordered according to final rank 81
Figure 4.11. Themes arising from Question 5: ‘How does South African activities of daily living differ from western activities of daily living?’, ordered according to final rank 85

LIST OF TABLES

Table 2.1. Bathing item in the Modified Barthel Index 15

Table 2.2. Toileting items in the Modified Barthel Index 17

Table 2.3. Toilet hygiene item in the Modified Barthel Index 20

Table 2.4. Dressing item in the Modified Barthel Index 21

Table 2.5. Feeding item in the Modified Barthel Index 24

Table 2.6. Functional mobility items in the Modified Barthel Index 27

Table 2.7. Grooming item in the Modified Barthel Index..... 31

Table 2.8. Comparison of Activities of Daily Living frameworks to the Modified Barthel Index and their application in the South African context 34

Table 2.9. Summary of the psychometric properties of the most common versions of the Barthel Index 40

Table 3.1. Table of Specifications for content validity 46

Table 3.2. Outline of Table of Specifications applied to this study (Content validity of Modified Barthel Index in stroke patients in South Africa) 47

Table 3.3. The five questions posed to the four nominal group technique groups ... 57

Table 3.4. Example of data capturing format according to Van Breda (79) 59

Table 3.5. Calculating final rank scores for each theme according to Van Breda (79) 61

Table 4.1. Themes arising from Question 1: ‘Who should administer the Modified Barthel Index?’ 68

Table 4.2. Themes arising from Question 2: ‘What language should the Modified Barthel Index be in?’..... 70

Table 4.3. Themes arising from Question 3: ‘How can we rephrase the Modified Barthel Index to make it more clear and understandable?’ 73

Table 4.4. Suggested word substitutions by participants..... 76
Table 4.5. Suggested key for quantifying words/amount of assistance in MBI..... 76
Table 4.6. Themes arising from Question 4: ‘Compare the Practice Framework to the Modified Barthel Index. Are there any items of the Modified Barthel Index you would include/exclude?’..... 78
Table 4.7. Themes arising from Question 5: How does South African activities of daily living differ from western activities of daily living?..... 82
Table 7.1. List of statements generated by four nominal group technique discussion groups for Question 1, sorted according to theme 123
Table 7.2. Rankings of Question 1 themes, sorted according to final rank..... 124
Table 7.3. List of statements generated by four nominal group technique discussion groups for Question 2, sorted according to theme 125
Table 7.4. Rankings of Question 2 themes, sorted according to final rank..... 127
Table 7.5. List of statements generated by four nominal group technique discussion groups for Question 3, sorted according to theme 127
Table 7.6. Rankings of Question 3 themes, sorted according to final rank..... 130
Table 7.7. List of statements generated by four nominal group technique discussion groups for Question 4, sorted according to theme 131
Table 7.8. Rankings of Question 4 themes, sorted according to final rank..... 134
Table 7.9. List of statements generated by four nominal group technique discussion groups for Question 5, sorted according to theme 135
Table 7.10. Rankings of Question 5 themes, sorted according to final rank..... 137

LIST OF ABBREVIATIONS

ADL:	Activities of Daily Living
BI:	Barthel Index
CVA:	Cerebrovascular accident (referred to as 'stroke' in this study)
CVI:	Cerebrovascular incident (referred to as 'stroke' in this study)
EBP:	Evidence-based practice
FIM:	Functional Independence Measure
HCW:	Healthcare worker
ICF:	International Classification of Functioning, Disability and Health
MBI:	Modified Barthel Index (Shah version)
MDT:	Multi-disciplinary team
NGT:	Nominal Group Technique
OT:	Occupational Therapist
OTPFIII:	Occupational Therapy Practice Framework (3rd edition)
PT:	Physiotherapist
TOS:	Table of Specifications
TUKS:	University of Pretoria
UCT:	University of Cape Town
UFS:	University of the Free State
UK:	United Kingdom
USA:	United States of America
UWC:	University of the Western Cape
SA:	South Africa
SMU:	Sefako Makgatho University
WHO:	World Health Organization
WITS:	University of the Witwatersrand

CHAPTER 1

INTRODUCTION AND BACKGROUND

1.1. Introduction to the Study

The Barthel Index (BI) is considered the global golden standard for assessing of one's performance in activities of daily living (ADL) tasks such as bathing, feeding and washing oneself (1,2). The Barthel Index has been shown to be a suitable outcome measure to specifically assess stroke patients' ADL functioning (1), but little research has been performed on the integrity of this outcome measure in the South African context. However, one version of the BI – the Modified Barthel Index (MBI) – has been studied in various developing nations in order to determine the content validity of the MBI in non-western societies – providing insight into the contextual and cultural factors that affect validity for the purposes of this study (3–5). Furthermore, despite being developed and adapted in a western country, the fact that the MBI is an easy-to-administer, cost-free, accessible and brief outcome measure, made it a potentially fitting tool for the South African context (3).

South Africa is a diverse nation with a wide variety of cultures, languages, races and religious beliefs. South Africa's population is approximately 54.9 million with the majority being African (80.5%), followed by Coloured (8.8%), Caucasian (8.3%), and Indian/Asian (2.5%) people (6). The African population is divided into 4 main groups, namely the Sotho-Tswana, the Tsonga, the Venda, and the largest group being the Nguni (comprised of the Zulu, Xhosa, Ndebele and Swazi people). Caucasians are typically Afrikaners or English-speaking people being descendants from European immigrants. South Africa is geographically divided into 9 provinces, the smallest but most populous province being Gauteng accommodating nearly a quarter of the population (6). Socio-economic statuses vary greatly across South Africa; ranging from high income households to those living in poverty; the poor predominantly being Africans who were discriminated during the Apartheid era prior to South Africa's

democratic freedom movement in 1994. Due to its unique context, quite different to a developed nation, the validity of an outcome measure would need to be established for this population.

Determining the validity of an outcome measure for the South African population benefits therapists working in stroke rehabilitation as it aligns the field of neurorehabilitation with the worldwide movement toward evidence-based practice (EBP). Evidence-based practice encourages therapists to use valid and reliable outcome measures to generate objective results, as opposed to relying on subjective findings when assessing a patient. Currently, South African occupational therapists working in neurorehabilitation most commonly use 'general observations' in daily practice to evaluate patients (7). This has raised concern regarding the integrity of their assessment findings since observations can be biased, emphasizing the need to generate outcome measures appropriate for the South African population. Secondly, EBP encourages efficient intervention in rehabilitation by monitoring a patient's progress and evaluating the effectiveness of various interventions. This outcome-focused approach allows for functional goal-setting and treatment in order to improve efficiency and quality of service, reduce hospital stay, and develop effective treatment options – further justifying the need to validate outcome measures for the South African population. Lastly, a valid ADL outcome measure for the South African population would provide therapists with insight into the reality of a typical South African's ADL practices. This would encourage more realistic and appropriate goal-setting for community reintegration; making neurorehabilitation a more meaningful and valuable service to South African stroke patients. Therefore, the content validity of the MBI needed to be established for the South African stroke population in order to implement it as an effective ADL outcome measure in training and practice.

1.2. Statement of the Problem

Firstly, several studies have confirmed the construct and concurrent validity of the MBI (8), however little research has been done to investigate whether the ADL items that form the content of the MBI include all aspects of ADL from

current theories and frameworks. Worldwide there is therefore a lack of information regarding the content validity of the MBI.

Secondly, the literature has indicated that cultural factors influence the validity of the MBI (8). Since the content of the MBI is based on ADL practices of an affluent and western society, and the population of a developing African nation presents significantly different practices due to cultural, socioeconomic and environmental reasons (e.g. toileting on western toilet versus toileting outside using a dry toilet system), this raised concern for the appropriateness of the MBI for the South African population.

Lastly, there is a lack of research specifying the differences in ADL practices between African and western societies – and specifically – its effect on the content validity of the MBI for the South African context. No literature has suggested changes to the content or items of the MBI in order to standardize the tool for the South African stroke population.

1.3. Purpose of the Study

The purpose of the study was to evaluate the MBI with experienced neurorehabilitation physiotherapists and occupational therapists to determine the tool's content validity for stroke patients in the South African context and to recommend what modifications should be made to improve the its content validity for these patients.

This study ultimately aimed to contribute to the validation of an ADL outcome measure for the South African stroke population, adding to research and evidence-based practice in the field of neurorehabilitation to facilitate improved efficiency and effectiveness in assessment, goal setting and functional recovery in therapy.

1.4. Research Question

What is the content validity of the MBI when used to evaluate the ADL functioning of stroke patients in South Africa?

1.5. Aim of the Study

The study aimed to determine whether the content validity of the MBI is adequate in assessing the ADL functioning of stroke patients in South Africa.

1.6. Objectives

1.6.1. Objective 1

To determine whether all ADL items are included in the MBI according to current ADL theories and frameworks.

1.6.2. Objective 2

To determine whether the content (directions, content areas and instrument items) of the MBI is suitable for the South African population.

1.6.3. Objective 3

To identify any adjustments required for the MBI to be a standardised tool for the SA population

1.7. Justification of the Study

Research regarding reliable and valid outcomes measures is essential to improve EBP in neurorehabilitation in South Africa. Valid outcome measures allow therapists to set functional goals and determine the effectiveness of their neurorehabilitation interventions (9). Implementing effective intervention strategies in stroke rehabilitation leads to a higher likelihood of stroke survivors returning to work and contributing to the open labour market, a reduced demand for disability grants funded by the state, and a reduction in the liability placed on the healthcare system for chronic disease support services such as caregivers, various therapies, palliative care support and assistive devices. Overall, this study contributes knowledge regarding the validity of ADL outcome measures for the South African population for the advancement of the profession of occupational therapy and the field of neurorehabilitation in South Africa.

The study provided evidence for the content validity of the MBI, thereby contributing to EBP to raise the profession's profile by adding to best practice measures and effectiveness in therapy on a national and international level. The study also exposed the MBI to neurorehabilitation therapists as a possible outcome measure that can be used to assess South African stroke patients' ADL functioning in their daily practice or taught at an undergraduate level, further improving the use of outcome measures and EBP.

CHAPTER 2

LITERATURE REVIEW

2.1. Introduction to the Literature Review

The aim of this chapter is to outline the framework used to assess a stroke patient's functioning in their ADL, and to examine the various perspectives of the literature regarding the content of an ADL outcome measure; the MBI.

Firstly, the burden of a stroke and the aim of functional recovery in ADL in stroke rehabilitation is discussed. Secondly, the theory of ADL is explored. Thirdly, a background to the ADL outcome measure; the BI, and the South African context is given. Fourthly, the ADL theory is then applied to the stroke population, the South African context, and the content of the MBI. Lastly, the chapter concludes by examining the integrity of the MBI, with a particular focus on the need to establish the content validity of the MBI for the South African stroke population.

2.2. Stroke

Also known as a cerebrovascular incident/accident (CVI/CVA), a stroke is a chronic, non-communicable disease, primarily caused by unhealthy lifestyle habits such as physical inactivity, unhealthy diets, smoking and drinking alcohol (10). These habits result in raised blood pressure, blood lipid and blood glucose levels, ultimately contributing to an interruption of the blood supply to the brain due to a burst or blocked cerebral blood vessel (10). The resulting neurological deficits of a stroke affect one's body functions and structures causing damage to the various cortices in the brain. The most common body dysfunctions following a stroke are weakness (loss of motor power and control) and absent or diminished sensation on the contralateral side of the lesion, slurred speech (dysarthria), language difficulties (aphasia), impaired swallowing (dysphagia), visual field loss (e.g. homonymous hemianopsia), perceptual difficulties, low energy and drive, cognitive deficits (e.g. disorientation, poor attention, memory loss, etc.), personality and temperament changes, and gait pattern dysfunction (11). The effect of these impairments compounded by environmental and personal barriers (e.g. poor environmental accessibility) leads to occupational dysfunction or disability - an inability to engage in meaningful, daily tasks

independently. This disability renders most stroke survivors with limited functioning in ADL, such as feeding, bathing and dressing thus leaving them dependent on caregivers to assist them in performing these tasks (12,13). This burden of death and disability caused by strokes further drains already poverty-stricken developing nations such as South Africa. With strokes being the third leading cause of disability worldwide (14), one African study warns that "the burden of stroke will increase to epidemic proportions unless interventions are set in place" (15, page 276).

2.3. Stroke Rehabilitation

Stroke prevention initiatives are the recommended first line of defense in relieving the incidence and burden of stroke (16). But what can one do when the damage is already done? Strokes are one of the leading causes of disability in South Africa, resulting in a high population of people with severe disabilities that are reliant on caregivers and the health system (15). Stroke rehabilitation aims to promote recovery and the functional independence of stroke survivors in order to reduce disability and caregiver burden. This treatment is brought about on an individual level to the stroke survivor through various forms of rehabilitation by a multidisciplinary team (MDT) of healthcare professionals (e.g. neurologists, occupational therapists, physiotherapists, speech and language therapists, community healthcare workers, etc.) and caregivers. Treatment in stroke rehabilitation has shifted its focus over the past few decades from remediating body functions and structures (e.g. improving muscle strength) to a more task-orientated approach (e.g. gaining independence in feeding oneself) (12). This is because stroke rehabilitation affirms the belief that body structure and function impairments do not necessarily predict levels of disability or functional independence (12). Furthermore, pursuing improved functional independence in acute stroke survivors is a more valuable quest as a nation because if successful, it can have a larger effect on the economy and health system by relieving the nation from the burden of cerebrovascular disease (17). Improved functional independence in stroke survivors lends to a higher likelihood of returning to work and contributing to the open labour market, a reduced demand for disability grants funded by the state, and a reduction in the liability placed on the healthcare

system for chronic disease support services such as caregivers, various therapies, palliative care support and assistive devices (17).

Occupational therapists form a crucial part of the stroke rehabilitation team because their focus of treatment is on the patient's functional recovery in their ADL and domestic life (12,18). Improving a patient's independence in their performance of their ADL, such as feeding, bathing and dressing are typically an occupational therapist's first focus – as opposed to social skills or work functioning, because these personal management tasks are crucial for survival (19). In order to understand a patient's level of independence in self-care tasks, 'ADL' needs to be discussed in further detail.

2.4. What are Activities of Daily Living?

2.4.1. Activities of Daily Living as defined by the Occupational Therapy Practice Framework and International Classification of Functioning, Disability and Health

Activities of daily living, also referred to as self-care tasks, are "activities that are oriented toward taking care of one's own body" (19, page S19). Self-care tasks (e.g. bathing, dressing, toileting, etc.) form one of the major domains of everyday life-participation essential for functioning independently.

Chapter 5 Self-care
d510 Washing oneself
d520 Caring for body parts
d530 Toileting
d540 Dressing
d550 Eating
d560 Drinking
d570 Looking after one's health
d598 Self-care, other specified
d599 Self-care, unspecified

Figure 2.1. Self-care domain as defined in the International Classification of Functioning, Disability and Health

In an attempt to develop a unanimous structure by which countries can classify functioning, the World Health Organization (WHO) produced the ICF manual in 2001 (20). The ICF aims to broaden the universal understanding of functioning and disability to include the individual's environment and social context (20); in harmony with the client-centered philosophy of occupational therapy. Firstly, the ICF describes 'Body Functions' as the physiological and psychological functions of the body and 'Body Structures' as anatomical parts of the body such as organs, limbs and

their components – these form the basis of the previously accepted biological/medical model from which impairments stem (20). Secondly, the ICF includes ‘Activity’ as the execution of a task or action by an individual (e.g. toileting, washing oneself, or dressing), and ‘Participation’ as the involvement in a life situation (e.g. the ability to independently care for oneself) (20). Self-care forms one of nine participation domains in the ICF, and Figure 2.1. details the activities that constitute self-care. The ICF model illustrates a direct relationship between ‘Body functions and structures’ and ‘Activity’, and between ‘Activity’ and ‘Participation’; indicating that these areas affect one another. All three of these areas are also affected by environmental and personal factors which either act as a barrier or facilitator to function – such as housing accessibility.

Another framework by which these domains or ‘areas of occupation’ (i.e. ADL, work, social participation, leisure, play, education, etc.) in which people engage, are defined in the latest edition of the OTPFIII, published by the American Journal of Occupational Therapy in 2014 (19). The OTPFIII utilizes the ICF as a basis for the terminology and criteria used in classifying client factors; specific impaired body functions and structures, so that a universal language by which occupational therapists assess and treat clients can be established. Furthermore, the OTPFIII forms a construct which outlines all elements within each domain or ‘area of occupation’ which overlap both of the ICF’s ‘Activity’ and ‘Participation’ fields (19). Consequently, ADL functioning as defined by the OTPFIII as shown in Figure 2.2, lists similar activities to the ICF’s self-care domain as seen in Figure 2.1.

Category	Description
ACTIVITIES OF DAILY LIVING (ADLs)—Activities oriented toward taking care of one's own body (adapted from Rogers & Holm, 1994). ADLs also are referred to as *basic activities of daily living (BADLs)* and *personal activities of daily living (PADLs)*. These activities are "fundamental to living in a social world; they enable basic survival and well-being" (Christiansen & Hammecker, 2001, p. 156).	
Bathing, showering	Obtaining and using supplies; soaping, rinsing, and drying body parts; maintaining bathing position; and transferring to and from bathing positions
Toileting and toilet hygiene	Obtaining and using toileting supplies, managing clothing, maintaining toileting position, transferring to and from toileting position, cleaning body, and caring for menstrual and continence needs (including catheter, colostomy, and suppository management), as well as completing intentional control of bowel movements and urination and, if necessary, using equipment or agents for bladder control (Uniform Data System for Medical Rehabilitation, 1996, pp. III-20, III-24)
Dressing	Selecting clothing and accessories appropriate to time of day, weather, and occasion; obtaining clothing from storage area; dressing and undressing in a sequential fashion; fastening and adjusting clothing and shoes; and applying and removing personal devices, prosthetic devices, or splints
Swallowing/eating	Keeping and manipulating food or fluid in the mouth and swallowing it; *swallowing* is moving food from the mouth to the stomach
Feeding	Setting up, arranging, and bringing food [or fluid] from the plate or cup to the mouth; sometimes called *self-feeding*
Functional mobility	Moving from one position or place to another (during performance of everyday activities), such as in-bed mobility, wheelchair mobility, and transfers (e.g., wheelchair, bed, car, shower, tub, toilet, chair, floor). Includes functional ambulation and transportation of objects.
Personal device care	Using, cleaning, and maintaining personal care items, such as hearing aids, contact lenses, glasses, orthotics, prosthetics, adaptive equipment, glucometers, and contraceptive and sexual devices
Personal hygiene and grooming	Obtaining and using supplies; removing body hair (e.g., using razor, tweezers, lotion); applying and removing cosmetics; washing, drying, combing, styling, brushing, and trimming hair; caring for nails (hands and feet); caring for skin, ears, eyes, and nose; applying deodorant; cleaning mouth; brushing and flossing teeth; and removing, cleaning, and reinserting dental orthotics and prosthetics
Sexual activity	Engaging in activities that result in sexual satisfaction and/or meet relational or reproductive needs

Figure 2.2. Activities of Daily Living as defined in the Occupational Therapy Practice Framework (3rd edition)

*Permission to reproduce image granted by American Journal of Occupational Therapy via RightsLink® License Number: 3874230483087

ADL are most often one of the primary areas of focus in stroke rehabilitation (18) because independence in ADL is needed for basic independent survival and is often the greatest need of the client. However one must consider whether being fully independent in ADL is meaningful to all people. For example, some families take on a caregiver role toward their "sick" parent to show respect and care and fulfill their role as their child. Additionally, a client may prioritize another domain as more meaningful or important to them than acquiring independence in ADL. Therefore, one must be cautious to generalize a client's level of functioning in ADL to other domains.

2.5. An Activities of Daily Living Outcome Measure: The Barthel Index and Modified Barthel Index

2.5.1. Introduction to the Barthel Index

As discussed previously, the BI (available in several versions) is reportedly the best outcome measure in assessing one's ability to carry out one's self-care tasks (1,2); namely feeding, chair/bed transfers, grooming, toileting, bathing, ambulation (walking or wheelchair mobility), stair-climbing, dressing, and bowel and bladder management (2). The BI is one of the most used ADL indexes by health care workers, second to the modified Rankin scale (mRS) as the measure of choice (21). The BI and its various versions, are free, easily accessible, and shorter to administer compared to the mRS, and requires no formal training– this makes the BI the most reasonable and suitable outcome measure to be assessed in South Africa.

2.5.2. Development and versions of the Barthel Index

The BI was developed in the United States of America around 1955 and published by Mahoney and Barthel in 1965 due to its widespread popularity and usefulness (22). The publication briefly described its purpose as a tool which scores a patient's functional improvement throughout rehabilitation (22). The original BI is a 10 item ADL index which scores patient's independence in feeding, wheelchair transfers, grooming, toilet transfers, bathing, walking, stair climbing, dressing, and bowel and bladder continence. There are only two categories in which a patient can fall into; either 'with help', or 'independent'. A higher score is awarded for independence in the item, and a lower score if the patient requires assistance – totaling 100 points. The article also included a definition sheet which described each activities specifications.

In 1988, a 20-point version of the BI was published, which preserved the items and descriptions, but just adjusting the scoring (23). Soon afterwards, Shah et al. (1989) published a modified version of the original 100-point BI in the Australian Journal of Occupational Therapy which aimed to improve the sensitivity of the BI by introducing more categories of assistance, now known as the MBI (1) . Throughout the years, various authors have proposed further

modifications to the BI by reducing the amount of items (24,25), adding items (26), changing or expanding definitions (27), re-ordering scale items (28), changing the scoring (29), and translating it into various languages (3,4,30,31).

As outlined by one narrative review study, the variety of BIs available is confusing and complicates the literature (21). Many clinical studies describe their tool used as the 'Barthel Index' or 'Modified Barthel Index' without elaborating on the specific version or scoring method used (21). This distinction is imperative since various scales can produce substantial differences in scoring, and have varying psychometric properties (21). It is important to note that no version has been shown to be superior to others (21).

2.5.3. The Modified Barthel Index and its suitability for the South African context

Since no version of the BI is superior to any other, the researcher chose Shah et al.'s version of the BI – the MBI (Appendix A) - for this study based on the descriptions provided for each item allowing for detailed content analysis; previous content validity studies conducted on the MBI in other developing nations (more than any other version of the BI) providing insight into which items may be problematic or culturally loaded (3,4).

2.5.4. Language of the Modified Barthel Index for the South African context

The most widely recognized and used versions of the BI – the original American BI, British 20-point BI and 5-item BI, and the Australian MBI - were all published in English (1,22–24). Following the popularity of the tool, subsequent versions of the BI have been translated into different languages namely Turkish, German, Persian, Chinese, Brazilian, Dutch, Japanese and Italian (30). Furthermore, it has been suggested that some of the item descriptions in the BI and MBI should be revised/rephrased in order to improve clarity and avoid ambiguity in order to improve the reliability of the tool (3,32).

South Africa is a multilingual nation with 11 official languages, the most common home languages being isiZulu (22.7%), followed by isiXhosa (16%) and Afrikaans (13.5%) (33). However, 45% of South Africans are able to

understand and speak English as a lingua franca since it is the primary language of government, business and commerce (34). Additionally, English is the medium of instruction at most schools and training institutions, and therefore all formal communication amongst healthcare workers (HCWs) is in English. Since the MBI is based on direct observation of a patient's performance in ADL tasks, the tool is usually completed by HCWs and would therefore be suitable to remain in English. However, it is common for the HCW to ask the patient or friend/relative about a patient's performance in a specific area if it has not been observed which may require translation.

2.6. Practice Framework Aspects of Activities of Daily Living in a South African Context

The OTPFIII (19), published in 2014, is the 3rd edition of a framework currently used in South Africa and worldwide to classify patients' ADL functioning. A neurorehabilitation therapist's chosen outcome measure for assessment of a stroke patient's ADL functioning, such as the MBI, should reflect a current ADL construct such as the OTPFIII in order to ensure it remains relevant and assesses all necessary aspects of the ADL domain. However, most activity/participation-based outcome measures such as the MBI cannot be standardized over the global population due to the varying people groups, cultures, languages, environments and challenges each nation faces. For example, ADL are not the same for every person worldwide due to the discussed contributing factors (e.g. eating with hands versus eating with chopsticks or knife and fork). Furthermore, the SA context is diverse within itself and has some interesting challenges, not unlike other countries in the world, but is nevertheless unique. This emphasizes the importance of determining whether the content of the MBI is valid for the country in which it is used. The researcher has summarized all elements of the OTPFIII and applied it to the SA context, in an attempt to give background to the content validity of the MBI for stroke patients in SA. This also gives background to the methodology used for the current study.

2.6.1. Bathing, showering

According to the OTPFIII, 'bathing and showering' is an ADL activity which encompasses "obtaining and using supplies; soaping, rinsing, and drying body parts; maintaining bathing position; and transferring to and from bathing positions"(19, page S19). Similarly, the ICF lists 'washing oneself' as one of the seven core activities under the self-care (ADL) domain, this includes washing body parts and whole body, and drying oneself (20). The ICF does not include bath transfers as part of the activity as in the OTPFIII.

South Africa has a wide disparity of living conditions between the various cultures, classes, and geographical locations; therefore the practice of bathing in South Africa varies according to setting. In a South African study, it was found that urban (township) dwellers tend to bathe in baths, and rural dwellers tend to use a basin to wash (35). In one South African city, only 56% of households had plumbing inside their homes – the remaining 44% of households carried water from communal taps (36). Zinc bath tubs and basins are used as a substitute for baths in households without bathroom plumbing and 20 litre water containers are commonly used to carry water from a main water source (communal/ yard tap) to homes to fill these tubs and basins (36). It must be noted that bath transfers and bathing positions differ depending on which bath is used (e.g. standing, long sitting, short sitting), whereas the act of how one washes one's body appears to be universal. In South Africa, facecloths and soap bars are usually used instead of sponges, brushes, loofas or shower gel squeeze bottles, possibly due to costs.

In stroke patients, the ability to bathe is often affected due to the complexity of the task. Getting into a shower/tub requires the ability to transfer from sitting to standing, or to transfer from a wheelchair to a bath chair (assistive device) and one needs sufficient postural control and balance to maintain the bathing position. Washing is a difficult task for stroke patients; requiring bilateral arm and hand function to grasp the sponge and soap, reach all limbs and wash one's hair. Furthermore, patients without bathroom plumbing in South Africa

need to meet more physical demands (e.g. carrying water containers and filling the bath/basin) in order to be considered fully independent in this task.

Table 2.1. Bathing item in the Modified Barthel Index

BATHING SELF	**0**	Total dependence in bathing self.
	1	Assistance is required in all aspects of bathing..
	3	Assistance is required with either transfer to shower/bath or with washing or drying; including inability to complete a task because of condition or disease, etc.
	4	Supervision is required for safety in adjusting the water temperature, or in the transfer.
	5	The patient may use a bathtub, a shower, or take a complete sponge bath. The patient must be able to do all the steps of whichever method is employed without another person being present.

The MBI grades one's ability to perform this item from total dependence to complete independence. Full score for this item requires the person to be able to "use a bathtub, a shower, or take a complete sponge (bed bath) bath. The patient must be able to do all the steps of whichever method is employed without another person being present" (1, page 708). In a Japanese and Chinese study, the MBI bathing item was criticized for being a culturally loaded item as it does not include various methods of bathing, such as using a basin (3). This can be said for South Africa as many rural dwellers cleanse themselves by using basins or zinc tubs.

2.6.2. Toileting and toilet hygiene

2.6.2.1. Toileting (Bowel and bladder management)

Toileting (previously described as 'Bowel and bladder management') is grouped with toilet hygiene in the OTPFIII (see 2.7.2.2.), and is described as the "intentional control of bowel movements and urinary bladder and, if necessary, use of equipment or agents for bladder control" (19, page S19). The ICF lists 'defaecation' and 'urinary functions' under the body functions domain, rather than under the self-care (ADL) domain (20). 'Defaecation functions' includes the elimination of faeces and 'urinary functions'. It includes the act and control of urinating as well as the sense of having a full/empty bladder. Considering the following paragraph, it is important to note that the OTPFIII only includes equipment or agents needed for control of the bladder (e.g. catheter) – but not of the bowel.

Since this item describes a body function, it can be assumed that all human populations perform this excretory function similarly regardless of culture. However, in certain South African cultures, bowel and bladder cleansing is an important daily/weekly activity. Traditional herbalists (*inyangas*) and traditional healers (*isangomas*) may prescribe gastrointestinal cleansing rituals to rid spiritual possessions in order to restore an individual's health and spiritual harmony. These are performed by ingesting herbal laxatives or emetics (plant matter), or administering enemas. Despite the lack of literature in these bowel and bladder cleansing rituals, 80% of the South African black population uses the services of traditional healers (37), and therefore the everyday practice of this must not be overlooked. Enemas are particularly common practice – one 1995 study reported that a member of the Zulu community may administer up to 3 enemas a week (38).

The act of defaecating or urinating demands the appropriate sense or feeling of fullness of the bladder and colon, and the ability to contract the appropriate muscles to retain or void the contents. In colon cleansing, the patient requires gross and fine motor functioning and adequate cognitive functioning to prepare the water/medicine (*muti*), assume the correct position (lying or four-foot kneeling), insert the pipe/pump into the rectum and deliver the enema. Caregivers commonly use adult diapers to manage bladder and bowel incontinence of stroke patients (39); this requires the assistance of a caregiver to change and clean the client – an arduous task if the client is unable to assist in rolling onto their side or cleaning. The researcher has noted from clinical experience that as diapers are expensive and not freely available at clinics, poorer families do without and are more likely to employ unhygienic methods (e.g. towels).

Table 2.2. Toileting items in the Modified Barthel Index

BOWELS	**0**	The patient is bowel incontinent.
	2	The patient needs help to assume appropriate position, and with bowel movement facilitatory techniques.
	5	The patient can assume appropriate position, but cannot use facilitatory techniques or clean self without assistance and has frequent accidents. Assistance is required with incontinence aids such as pad, etc.
	8	The patient may require supervision with the use of suppository or enema and has occasional accidents.
	10	The patient can control bowels and has no accidents, can use suppository, or take an enema when necessary.
BLADDER	**0**	The patient is dependent in bladder management, is incontinent, or has indwelling catheter.
	2	The patient is incontinent but is able to assist with the application of an internal or external device.
	5	The patient is generally dry by day, but not at night and needs some assistance with the devices.
	8	The patient is generally dry by day and night, but may have an occasional accident or need minimal assistance with internal or external devices.
	10	The patient is able to control bladder day and night, and/or is independent with internal or external devices.

Bowel control and bladder control are independent items in the MBI. This item is scored out of 10; the lowest score granted for bowel incontinence, levels of assistance (attempts but unsafe; moderate help; minimal help) score incrementally higher, and the highest score demands the patient's intentional control of the bowels, having no accidents, and can use a suppository or take an enema when necessary. Compared to the original BI, the three separate levels of assistance in the MBI was created in an attempt to improve the sensitivity of the item, however, one study argued that it is unlikely that one would require 'moderate help' with bowel continence and it was therefore suggested that the three assistance response options be combined (as it is in the original BI) (2) . By combining assistance into one score, it was found that this resolved disordered thresholds in the Rasch analysis, thereby strengthening the content validity of the MBI (2). Furthermore, by removing the bowel control item completely from the MBI showed improvement in the fit of the data to the Rasch model – suggesting that the bowel control item is a likely measurement of another construct (i.e. not measuring ADL, but physiological body functions) (2). This finding is supported by two studies that found the continence items to misfit the single-dimension model (4,29). Also, in one South

African study (using the 20-point BI), it was found that bowel and bladder continence items scored higher (63% and 59% patients were independent in this item respectively) than any other items on discharge and at more than six weeks post-discharge (90% of patients were independent in both items) (40). Similarly, two other studies also found the continence items to be the easiest (2,3). These studies showing content misfit and disproportionate ease of task compared to other items is explained by one study that separated the two continence items from the other 'self-care' tasks and labelled them 'physiological needs', in-keeping with the ICF model, and explained that bladder and bowel functions are not common problems caused by brain lesions following a stroke (3). It is debatable whether the continence items should be removed from the MBI completely (2). However, as discussed earlier, enemas form an important task in some South African cultures and the inclusion of this in the MBI shows a suitable content needed for bowel control in the South African population.

2.6.2.2. Toilet hygiene

Similar to the ICF, the OTPFIII details toilet hygiene as "obtaining and using supplies, clothing management, maintaining toileting position, transferring to and from toileting position, cleaning the body, and caring for menstrual and [bowel and bladder] continence needs (19, page S19,20). The OTPFIII states that toilet hygiene includes using assistive devices such as catheters, colostomies, and suppository management. It is important to note that these global frameworks are not limited to specific environments or persons – outcome measures using these frameworks should reflect this principle, or ensure that all environments have been considered, especially when a variety of methods exist.

In South Africa, various sanitation services are used depending on culture, socioeconomic status and sanitary infrastructure (36). According to a recent national survey, the vast majority of South Africans (> 60%) have access to flushing toilets connected to a public sewerage system, as in western countries (41). The remainder of the population largely uses government subsidized pit latrines which are non-flushing toilets (hole in floor or seat) within a small

sheltered cubicle situated within 200 meters from the house. South Africa's poorest of the poor – and almost exclusively black – rely on the 'bucket system' (41). Standard buckets are provided by the municipality to households which men and women urinate and defecate into (used inside the home and kept outside) and are emptied once or twice per week by municipal sanitary personnel. If not emptied, contents are often poured into a dug out hole (36). Children are often encouraged to use the surrounding area (bushes, dug out holes) (36). Some areas have no sanitary infrastructure and use the bush (36). Additionally, not only does the structure of toileting in South Africa differ, but also the position and custom required to toilet. For example, traditional Indian people use flushing squatting toilets (squat over a hole in the floor) and clean themselves by washing themselves with their left hand, whereas Africans and Caucasians sit on a western toilet or bench and clean themselves by wiping with toilet-paper. The variety of toileting systems, customs and lack of accessibility to proper sanitation in South Africa creates an environmental barrier, especially to the disabled.

Toilet hygiene is often a priority concern for stroke patients and their caregivers. In hospital, acute stroke patients' toileting needs are managed by nurses – using urinary catheters and diapers. Despite only 34% of South African stroke patients achieving independence in toileting on discharge, catheters and diapers are removed – becoming an immediate stress on the family (40). Excluding bowel and bladder continence, stroke patients struggle to toilet for various reasons. Firstly, speech or language deficits lead to poor communication of toileting needs, motor deficits hinder the patient from managing to manipulate clothing or transfer to the toilet and assume the appropriate position (sit/squat) or to clean themselves. Lastly, cognitive or behavioural deficits lead to poor quality of performance and poor hygiene. Furthermore, the abovementioned environmental barriers, such as backyard pit latrines, create added burden and a great need for alternatives (low-cost commode, indoor bucket, etc.).

Table 2.3. Toilet hygiene item in the Modified Barthel Index

ON AND OFF THE TOILET	**0**	Fully dependent in toileting.
	2	Assistance required in all aspects of toileting.
	5	Assistance may be required with management of clothing, transferring, or washing hands.
	8	Supervision may be required for safety with normal toilet. A commode may be used at night but assistance is required for emptying and cleaning.
	10	The patient is able to get on/off the toilet, fasten clothing and use toilet paper without help. If necessary, the patient may use a bed pan or commode or urinal at night, but must be able to empty it and clean it.

Toilet hygiene is listed under 'on and off the toilet' (toilet transfers) in the MBI and the weight of the item is 10 points. In order to be awarded full score for the item, the patient must be able to get on and off the toilet, undress and dress, prevent soiling of clothes and use toilet paper independently (1). It also includes that if the patient requires a bed pan, commode, or urinal, but they must be able to empty it and clean it (1). As seen frequently in other MBI items, this item does not include obtaining supplies as described in the OTPFIII and ICF, which is a crucial aspect of toileting for some South Africans (e.g. fetching bucket). It is important to remember that the MBI considers catheters, suppositories, etc. under the continence items (bowel and bladder control), however it is of concern to the researcher that menstrual care has never been included in any version of the BI, especially since South Africa tends to treat a younger stroke population (42). Additionally, neither the MBI nor one of the frameworks consider whether the patient is able to get rid of the toilet waste (e.g. flushing the toilet, emptying contents of bucket, covering dug out hole, etc.) or access the toilet – a crucial aspect of toileting in rural South Africa. Furthermore, this item is arguably another culturally loaded item since the MBI assumes the patient uses a normal toilet (i.e. western toilet), rather than perhaps squatting over a bucket or hole as in South Africa. Similar concerns have been raised by other authors regarding this item (3,43).

2.6.3. Dressing

Dressing encompasses "selecting clothing and accessories appropriate to time of day, weather, and occasion; obtaining clothing from storage area; dressing and undressing in a sequential fashion; fastening and adjusting clothing and shoes; and applying and removing personal devices, prostheses, or orthoses"

(19, page S19) and is an essential self-care activity listed under the ICF (20). Similarly to the OTPFIII, the ICF includes the putting and taking off of clothes and footwear, and choosing appropriate clothing.

The ability to dress oneself independently is a meaningful activity to adult South Africans, regardless of setting or culture. Due to the diversity of the South African nation, types of clothing and accessories differ widely between tribes, religions and ethnic groups. Urban dwellers tend to increasingly wear western clothing, whereas rural groups tend to dress in their cultural wear (44). Traditional dress codes typically require women to wear skirts or dresses, blankets, headdresses and jewellery. African men traditionally wear animal skins or blankets, whereas Indian men wear a coat-like garment (*sherwani*) and turbans.

Dressing, similar to bathing, is a complex bilateral upper limb activity which demands voluntary arm movement and hand dexterity for fine motor dressing tasks (e.g. buttoning or tying laces). Occupational therapists teach stroke patients compensatory methods of dressing (one-handed dressing) when the paretic arm/ leg is unable to assist in dressing and may recommend adapting clothes or prescribing assistive devices (e.g. buttoning hook) to promote independence. The methods of one-handed dressing trained to South African occupational therapists is based on the assumption that the patient wears western clothing – no adaptations or compensatory techniques based on dressing in African clothing (e.g. wrapping a headdress) has been published.

Table 2.4. Dressing item in the Modified Barthel Index

DRESSING	**0**	The patient is dependent in all aspects of dressing and is unable to participate in the activity.
	2	The patient is able to participate to some degree, but is dependent in all aspects of dressing.
	5	Assistance is needed in putting on, and/or removing any clothing.
	8	Only minimal assistance is required with fastening clothing such as buttons, zips, bra, shoes, etc.
	10	The patient is able to put on, remove, corset, braces, as prescribed.

The MBI scores dressing out of ten, awarding full score to a patient who is able to put on, remove, and fasten clothing, tie shoelaces, or put on, fasten, remove corsets and braces, as prescribed (1). Since the MBI uses 'clothing' as the

descriptor and is not partial to the clothing items to be used, it can be assumed that this includes cultural attire such as headdresses and animal skins. Notably, the MBI includes applying/removing orthotics, but excludes the task of selecting appropriate clothing and obtaining it from a storage area, as described in the OTPFIII and ICF. One study comparing the inter-rater reliability of the 100-point BI and MBI to the Functional Independence Measure (FIM), found that all items of the MBI showed moderate to good inter-rater reliability (32). However, the 'dressing' item received the lowest average kappa scores for both versions of the BI and was attributed to possible ambiguity in the operational definitions (32). The authors therefore recommended revision of the definitions and that dressing be separately scored for upper and lower body (32), whereas another author just recommended that training should be provided for the item (8). In contrast, a later study found the dressing item to have a high negative fit residual to the Rasch model, indicating item redundancy or over discrimination (2).

2.6.4. Swallowing/Eating

Succeeding the act of feeding (see 2.7.5.), eating is "the process of keeping and manipulating food/fluid in the mouth and safely swallowing it" as described by the OTPFIII (19, page S19). Confusingly, the ICF does list 'eating' as an ADL but the description does not match the OTPFIII's 'eating' description, but rather the OTPFIII's 'feeding' description as discussed later (20). The ICF's 'swallowing' description under the body functions domain fits more appropriately; "functions of clearing the food and drink through the oral cavity, pharynx and oesophagus into the stomach at an appropriate rate and speed"(20, page 82). And since this item describes a body function, it can be assumed that all human populations perform this function similarly regardless of culture.

Stroke patients are at a fatal risk of aspiration pneumonia due to dysphagia. Volitional swallowing involves a complex sequence of cortical sensory and motor processes which result in a safe, voluntary swallow when eating (45). However in strokes, damage to the cortex or brainstem often impairs one's ability to clear food from the oesophagus without it impeding the respiratory

system. This difficulty in swallowing, or dysphagia, can result in various secondary complications such as weight loss, malnutrition, dehydration, avoidance of social dining, choking or food entering the airway (45). Food entering the airway without being cleared, or aspiration, is an independent predictor of mortality due to the rapid progression of bacterial infection developing into sepsis or recurrent pneumonia.

One systematic review reported a 37% - 78% global incidence of dysphagia in patients diagnosed with acute strokes (46). This finding is supported by South African literature which estimates a 56% incidence of dysphagia in acute South African stroke patients (47) – indicating a high incidence of swallowing difficulties due to strokes regardless of socio-economic factors. Furthermore, one study conducted in South Africa found that impaired swallowing on discharge was an independent predictor of mortality with aspiration pneumonia being one of the most commonly cited causes of death for these patients (48).

Eating is not listed as an item in any versions of the BI, probably because it is considered a body function, not a self-care item. This is debatable since bowel and bladder continence are considered items, however no literature has argued this. In addition, no ADL outcome measure which included ‘eating’ as an item could be found.

2.6.5. Feeding

Feeding is “the process of setting up, arranging, and bringing food or fluids from the plate or cup to the mouth” (19, page S19); this involves repetitively manipulating portions of food to the mouth with the appropriate utensils. Similarly, the ICF describes these actions under ‘eating’ and ‘drinking’ as self-care tasks and explicitly mentions that these actions include culturally acceptable ways of feeding (20).

Feeding habits amongst South Africans vary widely depending on culture, class and location. Traditionally, African and Indian ethnic groups eat from communal plates whilst seated on the floor using one or both hands to roll firm maize porridge (*mielie-pap*) or break bread and dip it in the side-dish of meat, gravy,

or vegetables before putting it into the mouth. Customarily, utensils were homemade from raw materials (wood, clay), for example soft porridge would be eaten with spoons and sour milk or beer was drunk from clay pots or hard-shell containers (*calabashes*) (49). Although rural communities still tend to conform to traditional etiquette, semi-urban and urban dwellers are becoming increasingly westernized in their feeding habits. English, Afrikaans and westernized Africans feed themselves using a metal knife, fork and spoon whilst seated at a table or eating off their lap or a low stool. Food is served from a communal bowl or individual plates and fluid is served in glasses or mugs.

Feeding is often one of the first activities in which a stroke patient is motivated to gain independence as feeding is a primary survival skill and intrinsically motivating. Although feeding is typically a bilateral upper limb activity; with both hands holding utensils, or one hand stabilizing the dish and the other scooping food into their hand or spoon; feeding can still be a successful one-handed activity. Due to this, many stroke patients compensate for loss of unilateral arm weakness by using their non-affected side to feed themselves – even if it isn't their dominant hand.

Table 2.5. Feeding item in the Modified Barthel Index

FEEDING	**0**	Dependent in all aspects and needs to be fed.
	2	Can manipulate an eating device, usually a spoon, but someone must provide active assistance during the meal.
	5	Able to feed self with supervision. Assistance is required with associated tasks such as putting milk/sugar into tea, salt, pepper, spreading butter, turning a plate or other "set up" activities.
	8	Independence in feeding with prepared tray, except may need meat cut, milk carton opened or jar lid etc. The presence of another person is not required.
	10	The patient can feed self from a tray or table when someone puts the food within reach. The patient must put on an assistive device if needed, cut food, and if desired use salt and pepper, spread butter, etc.

'Feeding' is listed as an item in the MBI. In order to score full independence (score ten), the patient should be able to feed themselves if the food is set-up and the patient must put on an assistive device if needed, cut food, and if desired, use salt and pepper, spread butter, etc. – incorporating all aspects described in the OTPFIII and ICF frameworks (1). In the literature, the feeding item consistently shows moderate to very good agreement for inter-rater

reliability across all versions of the BI (32,50,51). Feeding has also been found to be the easiest item (2,3), possibly due to the facilitating factors described above. However, one study criticized the MBI for being culturally loaded since it implies western utensils are used, as opposed to other utensils such as chopsticks for Chinese populations (3). Although Shah et al. suggests replacing the 'knife and fork' with 'chopsticks' in this case (52), one author argues that this culture-specific content means that the test cannot be directly translated into other languages, and the difference in difficulty in the task (chopsticks vs. knife and fork) influences the rating criteria (3). That said, the content of the feeding item in the MBI would be culturally acceptable for South Africans that use western utensils, however traditional Africans and Indian people use their hands which may be easier.

2.6.6. Functional mobility

Functional mobility is a broad term encompassing one's ability "to move from one position or place to another" (19, page S19). Although this activity is integrated into other ADL, it is comprised of the following activities: in-bed mobility, wheelchair mobility, transfers (wheelchair, bed, car, shower, tub, toilet, chair and floor), walking, and carrying objects (19). The ICF classifies 'mobility' under its own domain separate from self-care, and covers mobility extensively from lying down, carrying objects, and walking to driving cars or piloting aircrafts (20).

Loss of functional mobility is one of the most notable and devastating impairments following a stroke. Weakness (loss of motor control and muscle power), spasticity, joint instability, low muscle endurance and gait pattern abnormalities are common deficits following a stroke (11); all of these affecting activities related to mobility such as rolling in bed, moving around the house and climbing stairs in public. Additional sensory, cognitive, visual and perceptual difficulties compound the complexity of remediating this ADL. A priority focus in stroke rehabilitation – particularly physiotherapy - is improving a patient's balance, gait and movement functions (11). Occupational therapists take a more active role in wheelchair mobility and transfer training (transferring oneself safely from the wheelchair to the bed/bath/toilet/car etc.). In-bed

mobility is typically treated first in acute settings by training the patient to roll to both sides in bed and sit up. This is followed by improving moving from sit-to-stand and standing independently. Various therapies are then used to remediate gait (e.g. treadmill training) or provide assistance in walking (e.g. walking frames) (11). Although stair climbing is usually the last mobility item to be addressed in therapy due to its difficulty, it is nevertheless important as the literature reports it as one of the largest cause of falls in stroke survivors (53). If a patient is unable to walk safely, a wheelchair may be prescribed and the patient would be trained to utilize the wheelchair and transfer in/out of it as independently as possible.

South Africa's unforgiving terrain, space limitations (overcrowding) and informal dwellings in rural areas act as a barrier to the already mobility impaired. Contrastingly, one study investigating the environmental barriers to disabled urban and rural people in South Africa found that the natural and built environment was more of a problem for urban dwellers, compared to their rural counterparts (54). This was supported by the reason that stairs, escalators, and curbs in urban areas are just as much - if not more - of a barrier as rough terrain is in rural areas. On the whole, one author commented that the physical environment can pose a threat to the validity of MBI since differing natural and built environments may not mirror that of developed nations (3). Similarly, the home and rehabilitation environment may differ greatly, therefore the author of the MBI warns that score interpretation of the MBI should be exercised with caution and emphasizes that change in individual item scores are more meaningful to the therapist as they reveal where the primary deficits in functioning are (1).

Table 2.6. Functional mobility items in the Modified Barthel Index

CHAIR/BED TRANSFERS	**0**	Unable to participate in a transfer. Two attendants are required to transfer the patient with or without a mechanical device.
	3	Able to participate but maximum assistance of one other person is require in all aspects of the transfer.
	8	The transfer requires the assistance of one other person. Assistance may be required in any aspect of the transfer.
	12	The presence of another person is required either as a confidence measure, or to provide supervision for safety.
	15	The patient can safely approach the bed walking or in a wheelchair, lock brakes, lift footrests, or position walking aid, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, transfer back into it safely. The patient must be independent in all phases of this activity.
AMBULATION	**0**	Dependent in ambulation.
	3	Constant presence of one or more assistant is required during ambulation.
	8	Assistance is required with reaching aids and/or their manipulation. One person is required to offer assistance.
	12	The patient is independent in ambulation but unable to walk 50 metres/yards without help, or supervision is needed for confidence or safety in hazardous situations.
	15	The patient must be able to wear braces if required, lock and unlock these braces assume standing position, sit down, and place the necessary aids into position for use. The patient must be able to crutches, canes, or a walkarette, and walk 50 metres/yards without help or supervision.
WHEELCHAIR MANAGEMENT * Only use this item if the patient is rated "0" for ambulation, and then only if the patient has been trained in w/c management.	**0**	Dependent in wheelchair ambulation.
	1	Patient can propel self short distances on flat surface, but assistance is required for all other steps of wheelchair management.
	3	Presence of one person is necessary and constant assistance is required to manipulate chair to table, bed, etc.
	4	The patient can propel self for a reasonable duration over regularly encountered terrain. Minimal assistance may still be required in "tight corners" or to negotiate a kerb 100mm high.
	5	To propel wheelchair independently, the patient must be able to go around corners, turn around, manoeuvre the chair to a table, bed, toilet, etc. The patient must be able to push a chair at least 50 metres and negotiate a kerb.
STAIRS	**0**	The patient is unable to climb stairs.
	2	Assistance is required in all aspects of stairclimbing, including assistance with walking aids.
	5	The patient is able to ascend/descend but is unable to carry walking aids and needs supervision and assistance.
	8	Generally no assistance is required. At times supervision is required for safety due to morning stiffness, shortness of breath, etc.
	10	The patient is able to go up and down a flight of stairs safely without help or supervision. The patient is able to use hand rails, cane or crutches when needed and is able to carry these devices as he/she ascends or descends.

Four items of the MBI relate to mobility; namely 'On and off the toilet' (toilet transfers), 'Stairs', 'Ambulation' (or 'Wheelchair management'), and 'Chair/bed transfers'. The MBI excludes some functional mobility items listed in the

OTPFIII such as in-bed mobility which is a common rehabilitation goal in acute stroke rehabilitation – highlighting the well-known BI floor effect. That said, the 'chair/bed transfers' and 'ambulation' items in the 20-point BI were considered two of the three main predictors of total BI score indicating that priority mobility areas are included (25). On average, the 'stair climbing' item in the MBI is the most difficult item globally (2), supporting the afore-mentioned late treatment of it. Despite the inclusion of these various mobility items in the MBI, more detailed mobility outcome measures are recommended for clinical settings, such as the Rivermead mobility index, Timed up-and-go, 10 meter walk test, 6 minute walk test, and stair climbing test (11) whereas the MBI rather functions to give a therapist a broad understanding of its impact on ADL functioning.

2.6.7. Personal device care

Personal device care is described as one's ability to "use, clean, and maintain personal care items, such as hearing aids, contact lenses, glasses, orthotics, prosthetics, adaptive equipment, and contraceptive and sexual devices" (19, page S19) as an ADL under the OTPFIII. However, the ICF does not recognize personal device care as part of the self-care (ADL) domain, but rather as 'maintaining assistive devices (d6504)' under the domestic life (IADL) domain, despite the descriptor being almost identical to the OTPFIII (20).

Assistive devices are commonly used by stroke survivors to enhance their functioning. Wheelchairs, walking frames and walking sticks assist with mobility; assistive devices for the home help patients perform ADL tasks independently (e.g. commode for toileting, bath chairs for bathing, etc.), and orthotics (splints, slings) help patients manage their pain or motor deficits. It is of particular interest to the occupational therapist whether a client, or their caregiver, is able to maintain a prescribed assistive device (e.g. splint or pressure garment) as these orthotics restore or enhance function. However, the inability to maintain adequate care of the device can either cause harm to the client, waste expensive resources (e.g. not servicing one's wheelchair), or will not yield desired results; and it is therefore important to know whether a client is able to perform this task independently if assistance is available. Additionally,

many of these assistive devices are used in ADL tasks – which is possibly the reason occupational therapists listed it as an ADL in the OTPFIII.

In most parts of South Africa, assistive devices are in short supply. Long waiting lists and delayed provision of assistive devices are common due to frequent budget constraints and the lack of therapists (55). Furthermore, care and maintenance services (e.g. wheelchair repairs) are scarce, particularly in rural areas (55). This is compounded by poor user training by therapists to patients in the wear and care of their devices due to a gap of information between guidelines and practice (55). Overall, personal device care is not well supported by the South African healthcare system; leaving patient's empty-handed and responsible for the care and maintenance of their devices.

Although 'personal device care' is not listed as an item in the MBI, device use is heavily integrated into each item's description. For example; for independence in ambulation, "the patient must be able to wear braces if required, lock and unlock these braces … the patient must be able to use crutches, canes, or a walkarette,..", (1) and so on. However, it must be noted that caring and maintaining these assistive devices is *not* the same as applying/using a device in a task. Understanding the distinction between the two is important; the former implies caring for the device – similar to mending torn clothes – which is an instrumental activities of daily living (IADL), the latter implies using a device – similar to using clothes to dress – which is an ADL. Furthermore, the ability to perform this task is not applicable to all patients as some may not use assistive devices, or the caregiver assumes the role of caring for the device. Therefore, whether the item should be included in the MBI is debatable.

2.6.8. Personal hygiene and grooming

'Personal hygiene and grooming' as described by the OTPFIII, or 'caring for body parts' in the ICF, involves "obtaining and using supplies; removing body hair (use of razors, tweezers, lotions, etc.); applying and removing cosmetics; washing, drying, combing, styling, brushing, and trimming hair; caring for nails (hands and feet); caring for skin, ears, eyes, and nose; applying deodorant;

cleaning mouth; brushing and flossing teeth; or removing, cleaning, and re-inserting dental orthotics and prosthetics"(19, page S19,20).

Personal hygiene and grooming is an important activity for all cultures in South Africa. Certain practices in applying cosmetics and styling/brushing hair in South African cultures extend beyond what is understood in a western context. For example, 'applying cosmetics' would include traditional mud, clay and natural dyes which are used to ceremoniously decorate the faces and bodies of men and women, e.g. Indian henna designs and white-painted Xhosa initiates. Furthermore, black South African women style their hair in a variety of ways using braids, weaves or chemical treatments; compared to white South African women who cut, dye or use heat treatments to style their hair. Additionally, western grooming practices, such as the removal of body hair (e.g. waxing), nail care (e.g. nail extensions), and product use (e.g. antiperspirants and perfumes) are common practice, particularly in urban areas.

The decline in one's personal hygiene and grooming practices is a common phenomenon following a stroke. One qualitative study found that irrespective of age or length of time following the stroke, female stroke survivors reported an uncharacteristic lack of interest in their physical appearance and grooming practices, ultimately affecting spousal intimacy and sexual activity (56). In addition, the fine motor co-ordination, visual perceptual skills and creativity involved in applying cosmetics or styling one's hair compounds the complexity of grooming. However, one South African study using the 20-point BI found that 35% of patients were independent in grooming on hospital discharge which grew to 79% at more than six weeks post-discharge (40), indicating that functional improvements are made in grooming once a patient returns home despite its complexity and the neglect of it.

Table 2.7. Grooming item in the Modified Barthel Index

PERSONAL HYGIENE (Grooming)	**0**	The patient is unable to attend to personal hygiene and is dependent in all aspects.
	1	Assistance is required in all steps of personal hygiene, but patient able to make some contribution.
	3	Some assistance is required in one or more steps of personal hygiene.
	4	Patient is able to conduct his/her own personal hygiene but requires minimal assistance before and/or after the operation.
	5	The patient can wash his/her hands and face, comb hair, clean teeth and shave. A male patient may use any kind of razor but must insert the blade, or plug in the razor without help, as well as retrieve it from the drawer or cabinet. A female patient must apply her own make-up, if used, but need not braid or style her hair.

The MBI lists personal hygiene (grooming) as an item. In order to achieve a full score for the item, the participant should be able to wash his/her hands and face, comb hair, clean teeth and shave. The MBI most noticeably excludes nail care, skin care (applying deodorant and lotion), and the use of dental orthotics from the ICF. With regard to shaving, the MBI includes obtaining and using the supplies (e.g. electric razor), and also states that a female patient must apply her own make-up, if used, but need not braid or style her hair. Interestingly, hair styling is explicitly excluded from the MBI although it is included in the OTPFIII and ICF. Initial hair styling in African women (e.g. braiding, weaving or styling) is done by another person/professional, but daily maintenance, such as clipping in weaves, is an important daily task to preserve the style.

2.6.9. Sexual activity

Sexual activity is an ADL which is described as “any activity that results in sexual satisfaction” (19, page S19). In addition, the ICF describes sex as a “mental and physical function related to the sexual act, including the arousal, preparatory, orgasmic and resolution stages” (20, page 90). It is important to note that both frameworks acknowledge sexual activity as not only a bodily function, but also as a form of interpersonal relationship. The ICF describes a sexual relationship as an intimate relationship where one creates and maintains a relationship of a sexual nature with a spouse or other partner (20). Overall, sexual activity is a complex interaction of emotional, psychological, mental, physical and physiological processes which bring about a feeling of sexual satisfaction.

Research on sexual practices and behaviour in South Africa largely focus on the prevention or transmission of HIV since South Africa has the highest HIV-positive population and one of the highest teenage pregnancy rates in the world (57,58). This affords researchers the knowledge of any unique attitudes and behaviours South Africans may have regarding sex. Interestingly, it has been found that despite the focus of sex education and HIV prevention, discussing sex in South Africa is still largely taboo (59). And this is not limited to rural, traditional areas – one South African outcome measure excluded sexual functioning from both urban and rural versions because participants from both cohorts felt shocked and uncomfortable, especially if asked by young HCWs, as it was not considered culturally appropriate (35). The effects of this generalized attitude by South Africans results in a backlash including avoidance of contraception resulting in teenage pregnancies, rape, poor compliance to HIV testing and a lack of sexual healthcare (60). Secondly, this attitude ultimately results in sex being excluded from assessment and is often a forgotten area in stroke rehabilitation in South Africa (61).

No literature reporting sexual functioning in stroke patients in South Africa could be found. However, in a recent systematic review which investigates the social consequences for working-aged adults with stroke, research found that 5% to 76% of stroke survivors experienced problems in sexual functioning or a decreased frequency of sexual intercourse with their partners (62). Sexual functioning may be affected due to a multitude of physical or psychological deficits post-stroke. One article clarifies that physical impairments would affect sexual positions and movement during sex, whereas deficits in communication, cognition and behavior could affect the spousal relationship (63). Furthermore, medication and comorbid conditions disturb erectile and ejaculatory functions and one's libido (63). Interestingly, one study found that one's level of disability post-stroke, measured by the BI, had no significant correlation to one's libido (64). Studies have also investigated the effects of different stroke lesions in male patients; finding that right hemisphere lesions correlated with ejaculatory disorders and overall impaired sexual function, while left hemisphere lesions resulted in decreased libido – often as a result of depression (65–67).

Compared to the OTPFIII, all versions of the BI do not include sexual activity as an ADL. One study emphasizes that due to the BI's lack of assessment of psychosocial aspects (such as sexual functioning), a stroke patient's BI score may poorly represent the impact the stroke has had on the person's life and suggested that health-related quality of life (HRQoL) instruments, such as the Stroke-Specific Quality of Life Scale, should be used to supplement the BI (68). The omission of this item could mean that the MBI's content does not comprehensively assess all ADL of a stroke patient. However it is common to use more than one tool in practice supplement a general and broad assessment with a more comprehensive tool can provide detail of a patient's functioning in a specific task.

2.6.10. Summary: Important differences between the Occupational Therapy Practice Framework and International Classification of Functioning, Disability and Health domains of Activities of Daily Living compared to the Modified Barthel Index

A summary of the above-mentioned ADL as listed in the OTPFIII are tabulated below comparing the OTPFIII to the ICF, the context of South Africa (SA), and content of the MBI with regard to stroke patients:

Table 2.8. Comparison of Activities of Daily Living frameworks to the Modified Barthel Index and their application in the South African context

	ICF (20):	OTPFIII (19):	MBI (1):	SA
Bathing, Showering	Listed under the self-care domain (ADL) as 'Washing oneself'. Comprised of applying water and soap and cleaning materials to one's body in order to clean oneself, as well as drying oneself. Does not include bath transfer as part of activity (as in OTPFIII).	Comprised of: - Obtaining and using supplies - Soaping, - Rinsing - Drying body parts - Maintaining bathing position - Transferring to and from bathing positions	Bathing is included as an item in MBI. Arguably culturally loaded – assumes western bathing. Does not include 'obtaining supplies' (fetching water). Item may be redundant or over discriminative.	Variety of methods of bathing (basin, zinc tub, western bath). Water must often be fetched.
Toileting (Bowel And Bladder Control)	Not considered as an ADL, rather listed under body functions domain (Defaecation functions and Urinary functions).	Comprised of: - Completing intentional control of bowel movements and urination and - Using equipment or agents for bladder control.	Bowel control and bladder control are separate items in MBI. Both items show disproportionate ease of task and misfit to the Rasch model, indicating that it is not measuring ADL construct but physiological processes.	Gastrointestinal cleansing rituals (laxatives and enemas) are common part of spiritual practice in African cultures
Toilet Hygiene	Listed under self-care domain (ADL) as 'Toileting'. Does not include aids e.g. catheter, colostomy, etc. (as in OTPFIII).	Comprised of: - Obtaining and using toileting supplies - Managing clothing - Maintaining toileting position - Transferring to and from toileting position - Cleaning body - Caring for menstrual and continence needs (including catheter, colostomy, and suppository management)	'On and off the toilet' (toilet transfers) is included in MBI. Also includes assistive devices. Arguably culturally loaded as it assumes western toilet is used. Does not include 'obtaining supplies', menstrual care, or ridding toilet waste.	A variety of toilets and methods of toileting exist (squat toilet, western flushing toilets, pit latrines, bucket system, bush). Toilets often outside. Sometimes waste must be rid (thrown out).

	ICF (20):	OTPFIII (19):	MBI (1):	SA
Dressing	Listed under self-care domain (ADL) as 'Dressing'. It does not include applying and removing personal devices, prosthetic devices, or splints (as in OTPFIII).	Comprised of: - Selecting clothing and accessories appropriate to the time of day, weather, and occasion. - Obtaining clothing from a storage area. - Dressing and undressing in a sequential fashion. - Fastening and adjusting clothing and shoes. - Applying and removing personal devices, prosthetic devices, or splints.	It does not include 'selecting or obtaining clothing'. The item may be redundant or over discriminative. There is possible ambiguity in definitions. Recommended revision of dressing definition and separating upper and lower body dressing.	Traditional attire in men and women are different to western clothing, e.g. headdresses, blankets and turbans, however South Africans are becoming increasingly westernized.
Eating	Not considered as an ADL, rather listed under body functions domain (Swallowing).	Comprised of keeping and manipulating food or fluid in the mouth and swallowing it.	Not included in MBI as an item.	N/A. (SA population performs the same as global population)
Feeding	Listed as an ADL under self-care domain separately as 'Eating' and 'Drinking'.	Comprised of setting up, arranging, and bringing food or fluid from the plate or cup to the mouth.	Feeding is included as an item. It is arguably culturally loaded as it assumes western utensils are used.	Variety of methods of feeding (communal plates eat with hands or western utensils).
Functional Mobility	Not considered as an ADL, rather listed as its own domain 'Mobility' – includes an extensive list of mobility activities.	Comprised of moving from one position or place to another (during performance of everyday activities): - In-bed mobility - Wheelchair mobility - Transfers (e.g., wheelchair, bed, car, shower, tub, toilet, chair, floor). - Functional ambulation - Transportation of objects	MBI lists four mobility items separately: - 'Ambulation' (or ' 'Wheelchair management') - Stair climbing - Chair/ Bed transfer - 'On and off toilet' (includes transferring to toilet) Excludes all types of transfers, in-bed mobility and carrying objects (as in OTPFIII). Stair climbing is the most difficult item globally. Ambulation and chair/ bed transfers are two main predictors of the total BI score. Different natural and built environments may pose a threat to the validity of BI.	There are multiple natural and built environmental barriers to people with disabilities –these are most problematic in semi-urban areas due to space limitations and poor wheelchair accessibility.

	ICF (20):	OTPFIII (19):	MBI (1):	SA
Personal Device Care	Not considered as an ADL, rather listed under the domestic life domain as 'Maintaining assistive devices'.	Comprised of using, cleaning, and maintaining personal care items, such as hearing aids, contact lenses, glasses, orthotics, prosthetics, adaptive equipment, glucometers, and contraceptive and sexual devices.	Not included in MBI as an item.	Service and maintenance of assistive devices is not well supported in SA.
Grooming	Listed under the self-care domain as 'Caring for body parts' (ADL).	Comprised of: - Obtaining and using supplies - Removing body hair - Applying and removing cosmetics - Washing, drying, combing, styling, brushing, and trimming hair - Caring for nails (hands and feet) - Caring for skin, ears, eyes, and nose - Applying deodorant - Cleaning mouth - Removing, cleaning, and re-inserting dental orthotics and prosthetics	Personal hygiene included as an item. Excludes skin care, the use of dental orthotics, and hair styling.	Grooming in SA includes applying traditional cosmetics (e.g. clay face paintings, henna designs) and African hair styling. Western grooming practices (e.g. waxing for hair removal) are increasingly common in SA.
Sexual Activity	Listed under 'Body function and structures' domain and 'Interpersonal interaction and relationships' domain.	Comprised of engaging in activities that result in sexual satisfaction and/or meet relational or reproductive needs.	Not included in MBI as an item.	Discussing sex practices in South Africa is largely taboo and previously considered not culturally appropriate to be included in an outcome measure.

2.7. Psychometric Properties of the Barthel Index and its versions

At the beginning of this research report, the BI was introduced as the global golden standard of ADL assessment - this status is attributed to the BI's consistently unparalleled reliability and validity scores in various studies.

2.7.1. Reliability

A recent systematic review and meta-analysis evaluating the inter-rater reliability of the three main versions of the BI; namely the original 100-point BI (22), 20-point BI (23) and MBI (1); determined the overall weighted kappa statistic to be 0.93 (kw=0.93) indicating very good agreement (kw>0.80) between scorers (51). This finding is supported by an earlier systematic review with the same objective which found a high percentage agreement (70 – 100%) for total BI scores, however individual BI items were found to only have fair ($0.21 \leq k \leq 0.40$) to moderate ($0.41 \leq k \leq 0.60$) agreement (50). Both systematic reviews recommended that standardized training of the BI should be investigated to further improve the reliability of the test (50,51). One study that compared the inter-rater reliability of the original 100-point BI to the MBI found that both showed moderate to very good agreement; the BI's kappa scores ranged from 0.57 - 0.85 and the MBI's kappa scores ranged from 0.52 - 0.88 (32); concluding that no version of the BI to be superior.

Interestingly, despite the vast data available regarding the inter-rater reliability of the BI and its alternate versions, only one study could be found that has investigated its intra-rater (test-retest) reliability and no systematic review regarding this has been published. The one study reported that the 20-point BI had good test-retest reliability (reliability coefficient = 2.0) with little bias and low random error (69). Information regarding the intra-rater reliability of the MBI is needed (8).

2.7.2. Validity

An outcome measure's instrument validity determines whether the assessment tool "accurately measures what it is supposed to measure" (70). Validity therefore determines the integrity and appropriateness of the assessment tool.

The strength of the tool's validity can be determined in several ways; most commonly through analysis of its face validity, criterion-related validity (predictive and concurrent validity), construct validity and content validity (70).

The construct validity for the BI is well-established (8). Two studies verified the BI's excellent convergent construct validity; one study confirmed the 20-point BI and BI-5 correlated highly with FIM (r=0.93 and r=0.87 respectively) (24).; and another showed that the BI scores closely correlate with scores of the Fugl-Meyer motor assessment and the Berg balance scale (Pearson's $r \geq 0.78$, $p < 0.0001$) (8). BI scores are predicative of 6-month mortality, hospital length of stay and progress following stroke (71). Two studies found the predictive validity of the BI to be adequate; one study showed that lower BI admission scores were moderately associated with greater change in therapy (Spearman's rho = -0.42) (72); and another study showed that BI scores obtained at 14, 30, and 90 days after stroke moderately predicted the patient's Frenchay activities index score at 180 days post-stroke (Pearson's $r \geq 0.59$, $p < 0.0001$) (8). No recent studies reporting on the predicative validity of the MBI could be found. Another study, also in acute stroke patients, confirmed good concurrent validity between the 20-point BI and Motricity Index ($r = 0.774$) (73). This finding is supported by another study that found excellent correlation ($r \geq 0.92$) between acute stroke patients' FIM and the 20-point BI scores at both admission and discharge (74). Similarly, another study reported an excellent correlation between the MBI and FIM ($0.89 \leq r \leq 0.91$) (32); further indicating no version of the BI to be superior.

Interestingly, despite the multiple validity studies conducted on the BI and its versions, a rarely reported type of validity is content validity. Content validity is seen as the basis for determining other types of validity since it compares the representativeness of the items in the test to the framework which you are assessing (75). Although content validity is typically assessed before the actual scale is developed, it is essential to ensure test content is regularly revised to ensure it accurately reflects current theory and frameworks. That said, the items and descriptions of the MBI are the same as those described in the original BI; published in 1965, and there is no record or description of the construct on

which the BI is based. This dated content of the test requires urgent revision as part of determining its current content validity. All versions of the BI have only established the content validity for the countries it was developed in, and not for South Africa. Since the BI and MBI were originally developed in westernized nations, the MBI has not accounted for the environmental, language, cultural, and socioeconomic barriers that may influence ADL tasks.

There are no statistical tests to test content validity. Content validity is typically established through qualitative processes where a tool is presented to a group of experts/ jurors for subjective evaluation (70,76). However, some authors argue that content validity is best established by using both quantitative and qualitative methods to ensure that the data are congruent and unbiased (76,77).

Table 2.9. Summary of the psychometric properties of the most common versions of the Barthel Index

	100-point BI (22)	20-point BI (23)	MBI (1)	BI-5 (24)
Inter-rater reliability	Weighted kappa = 0.90 (95% CI, 0.85 to 0.94). Kappa values ranged from 0.70 for bowel control to 0.91 for bathing	Weighted kappa = 0.53 to 0.94 (median, 0.72) ICC was 0.94 with bathing and dressing lowest (moderate).	0.63 (toileting) - 0.85 (personal hygiene) kappa values (P< 0.001)	ICC = 0.90 to 20 point BI
	Kappa scores range from 0.57 (dressing) to 0.85 (feeding). ICC = 0.957	0.27 to 0.68. Bowels, transfer and dressing lowest (fair) and low crude agreement (transfers and dressing)	Kappa scores range from 0.52 (dressing) to 0.88 (feeding). ICC = 0.979	
	Systematic review: Kappa values in fair to moderate range with bowel item being lowest in 3 studies (as low as 0.17). ICC scores in 3 studies ranged from 0.89 to 0.97			
	Systematic review: Weighted kappa = 0.93			
Intra-rater (test-retest) reliability	Not established	Good test-retest reliability (reliability coefficient = 2.0) with little bias and low random error	Not established	Not established
Construct validity	Correlation with PULSES: Pearson r=-0/61 to -0.80	(Pearson's $r \geq 0.78$, $p < 0.0001$) 0.8 (14 DAS), 0.81 (30 DAS), 0.78 (90 DAS), 0.8 (180 DAS) with BI vs. Fugl-Meyer and 0.89, 0.94, 0.9, 0.91 with BI vs. Berg Balance Scale using the Pearson's product moment correlation coefficient	Not established	0.87 to FIM, 0.32 to London Handicap Scale, 0.22 to SF-36 PCS, 0.09 to SF-36 to SF-36 MCS
		0.93 to FIM, 0.37 to London Handicap Scale, 0.22 to SF-36 PCS, 0.14 to SF-36 MCS		
		Correlation coefficient r=0.729 (arm) r=0.751 (leg) and r=0.774 (total) BI vs. Motricity Index		

	100-point BI (22)	20-point BI (23)	MBI (1)	BI-5 (24)
Predictive validity	Spearman's correlation coefficient : Balanced sitting and bladder control at 1 week positively correlated with motor score at discharge (r=0.83), Barthel score at discharge (r=0.82) and walking score at discharge (r=0.94)	0.59 (14 DAS), 0.66 (30 DAS), 0.63 (90 DAS) predicitmg Frenchay activities index, r ≥ 0.59 at 180DAS	Not established	Not established
	Barthel is a predictor of health status (general, mental, emotional etc.)	Spearman's rho = -0.42 (negative association therefore lower score at admission shows greater improvement in rehab). Spearman's rho = 0.25 (positive association therefore % of goals achieved is greater when admission score is greater). Spearman's rho = 0.28 (positive association therefore % of goals achieved is greater when change in score is greater)		
		Admission BI score correlated with hospital length of stay (0.35), discharge home (0.63) and 3-month score (0.50)		
		Barthel scores were predictive of 6-month mortality, hospital length of stay and progress following stroke (Granger et al. 1977, Wylie 1967, Granger 1975)		
		Determines LOS. 1 point decrease in score predicts 1 day increase in LOS		

	100-point BI (22)	20-point BI (23)	MBI (1)	BI-5 (24)
Concurrent validity	Pearson correlation coefficient: BI and SIS ADL/IADL domain: 0.72-0.78. BI and SIS mobility domain: 0.69-0.70	0.92 (admission), 0.94 (discharge) using Spearman correlation coefficient. 0.83 (a), 0.87 (d/c) using ICC. BI vs. FIM	Correlation with MBI to BI ranged from 0.90 - 0.96. Correlation with MBI to FIM ranged from 0.89 - 0.91	0.74 (admission), 0.94 (discharge) using Spearman correlation coefficient. 0.36 (a), 0.74 (d/c) using ICC. BI-5 vs. BI 20-point
	Correlation of BI with MBI ranged from 0.90-0.96. Correlation with Bi and FIM ranged from 0.86 - 0.90	r = 0.95 correlated with BI (3 item) on admission		0.96 (92) to 20 point Barthel
		Good concurrent validity between the 20-point BI and Motricity Index (r = 0.774)		
Content validity	Not unidimensional (cannot sum scores to get a total for ADL function). The bladder item for the original Barthel Index had fit residuals of greater than 2, indicating the likely measurement of another construct. Transfers (-3.21) Toilet use (-2.01) fit residuals that exceeded -2 indicating item redundancy and overdiscrimination. Feeding, stairs, bowels, walking disordered thresholds. Walking is a disordered threshold on discharge scores - fits Rasch model when removed from test.	Not established	Not unidimensional (cannot sum scores to get a total for ADL function). The bladder and bowel items for the MBI had fit residuals of greater than 2, indicating the likely measurement of another construct. Toilet use (-3.92), Bathing (-3.13), Dressing (-2.63), Walking (-2.01) exceeded -2 indicating item redundancy and overdiscrimination. Stairs, bowels disordered thresholds. Stairs is a disordered threshold on discharge scores - still does not fit Rasch model when removed from test. The toilet use (2.3) and dressing (2.16) items had high negative fit residuals, indicating item redundancy on discharge scores.	Not established
			Feeding, toileting, bathing items are culturally loaded for Japanese/Chinese patients. Changing this might increase item difficulty and hence, rating criteria (e.g. using chopsticks is harder than using	

			a fork). However, content validity shouldn't be under threat when only using on that population. Physical environment can pose threat to validity of MBI	
			Shah et al. emphasizes that interpretation of the MBI must be exercised with care because the scoring of a persons ADL function may differ from rehab to home environment due to different constraints (i.e. we are assessing in a rehab setting for home reintegration)	

2.8. Conclusion of the literature review

This chapter emphasized the complexity of ADL and how culture, class and environment can act as barriers or facilitators to one's functioning in this area of occupation. Two global ADL frameworks, namely the ICF and OTPFIII, form the foundation of current ADL theory, outlining the tasks that constitute this domain. The BI has been considered the benchmark ADL outcome measure since the 1960's, however it is essential that this outcome measure reflects current theory. Furthermore, ADL outcome measures should also be appropriate and contextually relevant for the population it is testing. This chapter highlighted the need to determine whether the MBI accurately reflects the current ADL domain and its appropriateness for the South African stroke population. Each ADL task listed in the OTPFIII was defined, analysed for the stroke population, and then compared to the content of the MBI. The literature highlighted the strengths and weaknesses of the MBI and its appropriateness for the South African population.

The Barthel Index has endured a lot of criticism for not being culturally sensitive enough, however it remains the most feasible ADL outcome measure for the South African population since it is cost-free, brief, easily accessible and does not require formal training. The advantages of the BI being incorporated into the neurorehabilitation field in South Africa emphasizes the need for the establishment of its content validity for the South African stroke population.

CHAPTER 3

METHODOLOGY

3.1. Introduction

The following chapter describes the methodology used for this study. The outline of the approach to analysing content validity is first defined. Secondly, the study design, population and sample are explained, followed by the research measurements and procedure used for the study. Lastly the data analysis and ethical considerations for the study are described.

3.2. Research design

Due to the nature of this study and its research objectives, a mixed methods study design was used with a consensus-generating participatory methodology; the NGT. Data generated from four NGT groups were analysed using a combination of qualitative (content analysis) and quantitative (ranking) data analytic techniques. For this study, qualitative data would provide the researcher with valuable insights regarding South African neurorehabilitation therapists' experiences with stroke patients, and quantitative data would afford the researcher measurable, prioritized recommendations for the MBI which parallel the literature. The following outline describes the purpose and recommended method for using a mixed methods research design to establish the content validity of a tool.

3.2.1. An Outline to Analysing Content Validity

Consequently, a mixed methods approach was elected. In order to establish content validity using a mixed methods design, the following table of specifications (TOS) in Table 3.1. is suggested (76,78) as a TOS acts as a universal methodological structure which seeks to align all items of a test with all concepts that need to be assessed (78).

Table 3.1. Table of Specifications for content validity

Table of specifications
I. Establishment of a jury (panel) of jurors (experts) A. Create criteria for selection B. Identify potential jurors C. Select jurors D. Create directions for the work of jurors
II. Qualitative review of instrument components A. Appropriateness of instrument title B. Appropriateness of the directions for the instrument 1. Concise 2. Clarity 3. Complete C. Content areas covered 1. Appropriate 2. Complete D. Instrument items 1. Appropriateness 2. Clarity 3. Adequacy of response options for items E. Opportunity for revision of items F. Opportunity to recommend deleting an item G. Opportunity to add additional items to the instrument H. Opportunity for additional comments
III. Quantitative review of instrument components A. Determine rating scale B. Combine jurors'/panelists' ratings C. Eliminate those items that are not content valid

It is important to note that prior to analysing the content validity of a tool using the TOS, the researcher must clearly define the concept to be measured by reviewing the literature (76,77).

The above-mentioned literature review and TOS were applied to the MBI in this study. The details pertaining to this study are described in italics below each specification in Table 3.2.:

Table 3.2. Outline of Table of Specifications applied to this study (Content validity of Modified Barthel Index in stroke patients in South Africa)

Outline of TOS for content validity of the MBI
Defining the Concept: ○ *Literature review: The content of the MBI was analysed and compared to two ADL frameworks; the ICF and OTPFIII. These frameworks formed the foundation for conceptualizing the construct of ADL. Additionally, studies from varying fields that discussed items or the content of the MBI were included in the literature review and areas of consensus and disagreement on items/concepts were identified.*
I. Establishment of a jury (panel) of jurors (experts) A. Create criteria for selection ○ *Defining the jury: The study population, sample, inclusion and exclusion criteria are described in Chapter 3 (see 3.3.1).* B. Identify potential jurors ○ *Identifying the jury: The sampling method used for this study is described in Chapter 3 (see 3.3.2.2)* C. Select jurors ○ *Selecting the jury: The sample of jurors selected are described in Chapter 3 (see 3.3.2.1). Demographics of the sample is described in Chapter 4.* D. Create directions for the work of jurors ○ *Directing the jurors: The sample of jurors received an information letter prior to consenting to participate in the study which detailed what was required of them. Furthermore, each group of jurors received a brief orientation to the methodology of research prior to data collection.*

II. Qualitative review of instrument components

A. Appropriateness of instrument title:
   - *Instrument title: Not for discussion since tool is not in development phase – title has been established.*

B. Appropriateness of the directions for the instrument
   1. Concise
   2. Clarity
   3. Complete
   - *Directions for the instrument: No directions are provided for the MBI (as the tool should be understood on first impression) and therefore could not be evaluated. However, - as a comment on the instructions as a whole - the literature review emphasized that language is a common factor affecting the content validity of the MBI. The researcher therefore formulated the following two questions in order to determine whether the overall language used in the MBI was appropriate for the South African context as this section pertains to wording/language: 'Who should administer the MBI?' – this question was posed to the group first in order to orientate the jurors and researcher to who the jurors selected as the 'target audience' (i.e. who would be completing the MBI in the South African context), which lends itself to the language and wording style that should be ideally used in the test for this audience (e.g. language used for layperson versus professional). The second question posed to the group was 'Which language is best to use for the MBI?' – this question asked jurors to determine which language would be best to use for the aforementioned selected target audience since South Africa has a variety of languages (e.g. professionals use English whereas the majority of laypersons speak African languages). These questions were later elaborated on when wording of the items was examined.*

C. Content areas covered
   1. Appropriate
   2. Complete
   - *Question to jurors: 'What have you found differs in ADL tasks in South African patients compared to western patients?' This question encourages jurors to conceptualize all ADL tasks that South Africans engage in that may not be included in the MBI. This analyses the cultural appropriateness and completeness of the MBI for assessing South African ADL.*

D. Instrument items
   1. Appropriateness
   2. Clarity

- *<u>Question posed to jurors:</u> 'How can we rephrase the MBI to be more clear/understandable?' This question encourages jurors to not only identify problems with the MBI regarding appropriateness and clarity of the items, but also to generate solutions/recommendations.*

3. Adequacy of response options for items
   - *<u>Response options:</u> Not for discussion as evaluating scoring options was not a research objective for this study. However, the MBI was chosen due to its increased range of scores per item to improve the sensitivity of the tool.*

E. Opportunity for revision of items
   - *<u>Question for jurors:</u> This section was combined for the question posed for section D (generating solutions/recommendations to revise items)*

F. Opportunity to recommend deleting an item
   - *<u>Question to jurors:</u> 'Compare the OTPFIII to the MBI. Are there any items of the MBI you would exclude?' This question allows opportunity for jurors to delete items from the MBI.*

G. Opportunity to add additional items to the instrument
   - *<u>Question to jurors:</u> 'Compare the OTPFIII to the MBI. Are there any items of the MBI you would include?' This question allows opportunity for jurors to add additional items to the MBI.*

   *** The above two questions were later combined into one question posed to the jurors ('Compare the OTPFIII to the MBI. Are there any items of the MBI you would include/exclude?') in order to conform to time limitations.*

H. Opportunity for additional comments
   - *<u>Additional comments:</u> Encouraged throughout all questions to jurors – verbal group discussion was facilitated through each question. Researcher recorded additional comments as statements on which other jurors could vote.*

III. Quantitative review of instrument components

A. Determine rating scale
   - *<u>Rating scale:</u> The Nominal Group Technique (NGT) was identified and chosen as a suitable method for collecting quantitative and qualitative information simultaneously from the jury (Section II and III)* (79)*. This was done by posing the above-mentioned questions to the jury which were then discussed (qualitative) and recorded as statements, followed by a voting round whereby each juror ranked the importance of the statements generated by the group (quantitative) on a scale of 1 (most important – awarded 5 points) to 5 (least important – awarded 1 point). A step-by-step description of the NGT is given below (see 3.5.).*

B. Combine jurors'/panelists' ratings

- *<u>Combining ratings:</u> Final rank scores were tallied and standardized over the four groups in Chapter 4 to produce a final rank (quantitative) for the main themes emerging (qualitative) from the multi-group NGT data. This method allowed for an efficient, easy and integrated data collection process and has been shown to be a suitable method for establishing content validity* (35,80–82)*.*

C. Eliminate those items that are not content valid

Final recommended changes to MBI detailed in Chapter 5 based on the main themes that emerged for each question.

3.3. Study Population and Sample

3.3.1. Defining the jury: Study population

The population was defined as experienced occupational therapists and physiotherapists working in the field of neurological rehabilitation in Gauteng, South Africa. One occupational therapy study defined a therapist as 'experienced' once he/she accomplished five or more years working experience (83), however this study extended the inclusion criteria to include one participant with four years working experience once candidates had been exhausted.

It was not possible to define the parameter of the population as a South African database for occupational therapists and physiotherapists specializing or working in neurological rehabilitation does not exist. Although the Health Professions Council of South Africa (HPCSA) lists all registered occupational therapists and physiotherapists in South Africa – specialty and years of experience are not listed.

The Occupational Therapy Association of South Africa (OTASA) has a more detailed database, but membership is not compulsory for occupational therapists. Similarly, physiotherapists need not be a member of the South African Society of Physiotherapy (SASP). In both organizations, private practitioners constitute the majority of the membership due to the legal, advertising and training benefits. Using this database for the study would have been biased against therapists in the academic or government sector. Furthermore, occupational therapists and physiotherapists specializing in neurology are difficult to pinpoint as many fields in both professions exist. Practice in these fields can be interchanged freely as the undergraduate degree trains the therapist to work in all fields.

3.3.2. Defining the jury: Study sample

3.3.2.1. Selecting the jury: sample selection

The sample for this study consisted of 11 registered occupational therapists and 4 physiotherapists working in the city of Pretoria or Johannesburg, South

Africa. All participants (n=15) were working in the neurorehabilitation field in government, private or academic facilities at the time of data collection. Overall, four NGT groups were conducted over a period of 10 months.

3.3.2.2. Identifying the jury: sampling method

A snowball sampling method was employed. Locally known experienced therapists that met the study's inclusion criteria were contacted telephonically, invited to participate and then sent an information letter via e-mail and asked to suggest other therapists within Gauteng that comply with the inclusion criteria stated below. The suggested therapists were then also contacted and invited to participate. Additionally, hospitals, private neurorehabilitation centres, private practitioners and lecturers in Gauteng were listed and contacted telephonically in order to search for candidates for the study. The snowball sampling method was chosen due to the poorly defined population parameters of occupational therapists and physiotherapists working in neurorehabilitation with four or more years working experience. This method was particularly useful as many experienced therapists specializing in neurology closely network with other therapists in the same field and the majority of participants constituting the study sample were recruited through this method compared to contacting institutions without a reference.

3.3.2.3. Inclusion criteria

Commonly used criteria for the selection of jurors includes the candidate's job, experience, knowledge and availability (76). These factors were considered when defining the inclusion and exclusion criteria for participants. It was essential to include therapists currently working in the field of neurorehabilitation to ensure most recent evidence. The number of years of experience as a therapist was a minimum of four years as the researcher wanted to include therapists working in the government sector which largely consists of young therapists, most in their first few years of working. The inclusion criteria were as follows:

(i) Occupational therapists and physiotherapists registered with the Health Professions Council of South Africa (HPCSA)

(ii) At least four years of experience as a therapist (including community service year)
(iii) Currently working in the field of neurorehabilitation
(iv) Currently in Gauteng, South Africa
(v) Participants needn't be familiar with the BI or any version thereof
(vi) Participants may have received undergraduate training in another country

3.3.2.4. Exclusion criteria

None

3.4. Research Measurement

3.4.1. Measuring instruments

3.4.1.1. Demographic questionnaire

Demographic questionnaire (Appendix B) was developed for occupational therapists in a previous study (7). A piloting of this questionnaire was done on two physiotherapists that were not study participants prior to using it on participants to ensure the questionnaire was clear, easy to understand and unbiased between professions. The two pilot participants each received an information letter and consent form to be completed before piloting the questionnaire. The pilot participants were given hardcopies of the demographic questionnaire and were asked to write comments and suggestions regarding the questions in order for the questionnaire to be suitable, clear and user-friendly.

Subsequently, the following changes were made to the questionnaire:

(i) The title was changed to include 'physiotherapists'
(ii) 'Basic qualification' was changed to 'undergraduate qualification' to improve clarity
(iii) Year of undergraduate qualification was clarified by adding '(i.e. final year)'
(iv) 'Topics of all postgraduate degrees/courses' was clarified by adding '…which are relevant to neurological rehabilitation' and an extra line was added to create space for responses. Only postgraduate degrees/courses relevant to neurological rehabilitation were included in order to determine the extent of the experience each participant had in the neurorehabilitation field – the researcher would have chosen to present this information if

significant data arose from those who held the same postgraduate qualifications, or if it lent to the level of expertise of the groups.

(v) 'Years of experience as an occupational therapist' was changed from 'occupational therapist' to 'therapist' in order to include physiotherapists

(vi) Years of experience was clarified by adding '(incl. community service)' to clarify possible uncertainty

(vii) All questions were numbered

(viii) The last four questions regarding length of treatment, hospital stay and number of stroke patients were removed from the questionnaire as they were not relevant to the study

(ix) Two questions related to the BI were added by the researcher to the demographic questionnaire in order to determine the amount of training of BI (any version) was received by participants, and whether the BI (any version) is used in practice in South Africa by participants. The researcher chose to not ask specifically about training for the MBI - but rather any version of the BI - as there are many similar versions and the researcher wanted to gauge whether participants were familiar with it at all since previous research indicated poor training and usage of the tool (7).

3.4.1.2. Review of the literature

The purpose of the literature review was to understand and outline the construct of ADL as a whole and the tasks that constitute it. The two ADL frameworks (i.e. the ICF and OTPFIII) were selected for the literature review on the basis of their global recognition and usefulness. The ICF, developed by the WHO, serves as a global framework for the classification of body functions and structures, activities, and participation (includes 'self-care'/ADL as a domain) (20). The American OTPFIII, based on the ICF, provides a more detailed description of each self-care item (19).

The supporting literature included all articles reporting on the psychometric properties of the MBI from its year of development (1989) to the date of submission of this Master's research report (2016) as there are very few psychometric studies published on Shah et al.'s version of the BI. Searches of PubMed and Google Scholar for the BI and its versions were undertaken. Only

article titles referring to the psychometric properties (i.e. validity and reliability) of BI were perused. Only articles that used one of the four most recognized versions of the BI in their methodology were considered for inclusion, namely the American 100-point BI, the British 20-point BI and 5-item BI, and the Australian 100-point MBI. The researcher then identified specific areas from the literature which would lend to the clarity and understanding of the content of the MBI, or factors influencing the validity of the MBI, such as language, wording, environmental differences, and culture or item misfit in order to apply the ADL domain to the South African context.

3.4.1.3. NGT groups – Statements and voting cards

Four NGT groups were held over a period of 10 months. Each group was posed the same five questions and followed the same four step process of NGT groups (see 3.5). Each participant was given a notepad to silently generate ideas and record thoughts. A projector was used to display ideas/statements generated by the group. Participants privately ranked these statements from most-to-least important on a voting card after each question was discussed in the group as illustrated in Figure 3.1. Voting cards were collected at the end of the group and tallied by the researcher providing the researcher with quantitative data (ranked importance). For each card, the most important statement was awarded five points, whereas the least important was awarded one point and these ranked scores were standardized over all groups (see 3.6.2.). A collection of all statements generated per question were also a measuring instrument, as part of the final rank scores (ranked frequency). Details of how this data were analysed is discussed below (see 3.6.2.).

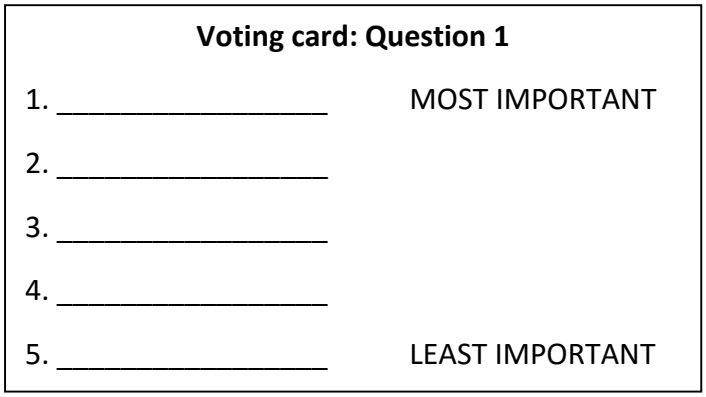


Figure 3.1. Voting card

3.5. Research Procedure

Permission was gained from original the publishers of the MBI (Journal of Clinical Epidemiology) on 27 February 2014, prior to data collection – License no. 3337210116859 - to use the test for the study (Appendix C). The research protocol was approved by University of the Witwatersrand occupational therapy department and postgraduate assessor group on 7 August 2013. Ethical clearance was granted from the University of the Witwatersrand Human Research Ethics Committee on 30 August 2013, Certificate no. M130810 (Appendix D)

The demographic questionnaire (Appendix B) was piloted on two physiotherapists. Relevant changes to the demographic questionnaire were made. Jury candidates were contacted telephonically and sent an information sheet and consent form: If the candidate expressed that he/she was willing to possibly participate, the researcher recorded their contact details (e-mail) and sent the information sheet (Appendix E) and informed consent letters (Appendix F, Appendix G).

Review of the literature: The key issues identified in the literature and inconsistencies with the OTPFIII and ICF structure formed part of the questions for the groups. Additionally, the suggested TOS process formed part of the questions posed to the groups – summarized below:

Table 3.3. The five questions posed to the four nominal group technique groups

Five questions posed to each group:
Question 1: Who should administer the Modified Barthel Index?
Question 2: What language should the Modified Barthel Index be in?
Question 3: How can we rephrase the Modified Barthel Index to make it more clear and understandable?
Question 4: Compare the Practice Framework to the Modified Barthel Index. Are there any items of the Modified Barthel Index you would include/exclude?
Question 5: How does South African activities of daily living differ from western activities of daily living?

Data collection: Four NGT groups consisting of three to six participants each were held between the November 2014 – August 2015 period. The number of participants per group varied due to the time and location as participants were spread out over the province, however a minimum of three participants was set to ensure discussion was possible. The NGT groups were arranged at venues in Pretoria and Johannesburg that were suitable and convenient to participants (arranged via e-mail/telephone). Tea and snacks were provided. All discussions were audio-recorded as evidence – it is important to note that the audio-recordings were not transcribed as is typically performed as part of a qualitative study's data analysis. In an NGT group, statements are formulated by participants and written down by a scribe for display to the group. These are the statements (listed in Appendix H) that are then used for data analysis and contribute to the formulated themes. Participants completed a consent form to be part of the study and to be audio recorded (Appendix F, Appendix G) prior to the group. Participants also each completed the demographic questionnaire.

The discussions were approximately 90 minutes in duration. Prior to the commencement of the group, participants were given an opportunity to peruse the MBI. The primary researcher moderated the groups. Group participants were expected to actively participate in responding to questions posed by the moderator formulated beforehand. The NGT follows four steps:

(i) Generating Ideas: The facilitator presented a question to the group in written form (projected by a Powerpoint presentation) and read the question to the group. The facilitator directed everyone to write ideas in brief phrases or statements on their notepads.

(ii) Recording Ideas: Participants engaged in a round-robin feedback session to concisely record each idea (without debate). The facilitator typed each statement as a bullet-point on a projected Powerpoint slide, whilst proceeding to ask for another idea from the next participant, and so on until all statements had been documented.

(iii) Discussing Ideas: Discussion regarding each statement was then facilitated to determine clarity, importance and consensus. The facilitator encouraged interaction and allowed every participant an opportunity to speak. Participants discussed each item in-depth (if found to be important) and compared it to current theory (ICF and OTPFIII) and clinical experience. Participants would discuss reasons why they agree or disagree with others statements.

(iv) Voting on Ideas: Participants each choose five statements from the list of statements generated that they found the most important regarding that question. Each participant voted privately on their voting cards by prioritizing the statements from one to five (one being the 'most important'). The statements not voted on are seen as the least important. Each voting card was collected and the votes were tallied to identify the ideas that are rated highest by the group as a whole. The statements that are the most highly rated by the group are the most favored group actions or ideas in response to the question posed by the facilitator.

3.6. Data Analysis

3.6.1. Demographic questionnaire

All demographic questionnaires were gathered and the raw data were entered into Microsoft Excel. Univariate analysis was done to describe the central tendency (mean, median), range and present frequency distributions of demographic questions. Graphs were used to illustrate the demographics of the sample as shown in the following chapter.

3.6.2. Analysing multi-group nominal group technique data to establish content validity

Van Breda's steps to analysing multi-group NGT data was used for this study (79). This data analysis process has been recommended to be used if analysis of combined data is an objective, as it was for this study (84).

(i) Step one: Data capturing

Firstly, the researcher captured data from each NGT group into an Excel Spreadsheet with each question posed to the group (five questions) having separate spreadsheets. Only statements that were voted on (i.e. received a score from the group) were captured, as this constituted the needed quantative data. All statements generated over the four NGT groups were captured; each statement was listed on the spreadsheet with its accompanying group number, summed scores received from votes (highest= 5 ponts points, lowest= 1 point), and the average score (sum of scores/number of persons in the group). The 'Theme' and 'Top 5' categories are described in later steps.

Table 3.4. Example of data capturing format according to Van Breda (79)

QUESTION 2					
Group	**Theme**	**Statement**	**Scores**	**Average**	**Top 5**
1		The most common African language (Zulu)	4+4+4+4	4.00	x
2		English because everyone has a general understanding	5+5+5+3+2	4.00	x
↓	↓	↓	↓	↓	↓

(ii) Step two: Identifying the top five

Secondly, the researcher first sorted the data according to group (first column) in ascending order so that all statements were grouped in progession from group one to four. Thereafter, the data were sorted

according to average in descending order (fifth column) so that statements were then arranged according to importance (highest averages for scores for each group listed first). The top five listed statements in each group are marked as 'Top 5' in the last column denoted by an 'x'.

(iii) Step three: Content analyse the data (qualitative)

Thirdly, the researcher listed all statements generated from each question over the four NGT groups. All statements were throughly perused and similar statements were grouped together into 'themes' whilst ensuring that all themes were mutually exclusive and collectively exhaustive. This process was repeated several times until the researcher was satified that all statements were allocated a theme, and all neccessary themes were generated and distinct from one another. Each theme was given a name, definition and number (second column) to be typed next to each statement.

(iv) Step four: Confirm the content analysis (qualitative)

Fourthly, four colleagues/volunteers who were not involved in the data analysis thus far were asked by the researcher to peer review the previous step. Van Breda motivates that this step is crucial to enhancing the inter-rater reliability of the study (79). The researcher gave a brief background to the study and the NGT process to all volunteers. Themes (with their descriptions) were provided with each questions. Each volunteer was separately e-mailed a list of all statements collected over the four NGT groups (statements were grouped per question). Each volunteer was required to allocate a theme to each statement, however if they felt a statement could fall into more than one category, or if they felt a statement didn't match any of the themes, they were asked to indicate that on the returned form. Once all completed lists were returned to the researcher, the group of volunteers convened to discuss any discrepancies. Each volunteer was provided with an opportunity to explain why they felt some themes were not mutually exclusive or if the list of themes was not collectively exhaustive. Themes were added, divided, combined and re-defined as a group until consensus on each theme-statement pairing was reached.

(v) Step five: Calculating combined ranks (quantitative)

This step involved calculating the relative importance of the themes generated over all four NGT groups. First, the researcher sorted all data

according to theme (column two) in ascending order so that all themes were grouped together. Secondly, the data were arranged according to Top 5 (last column) in descending order so that each theme's statements were ordered from most-to-least important. Thereafter, a second spreadsheet was created with the following headlines with Table 3.5. as an example:

Table 3.5. Calculating final rank scores for each theme according to Van Breda (79)

Theme	No. of Top 5	Ranked importance	Frequency of statements	Ranked frequency of statements	Average	Ranked averages	Final Rank
2B	6	5.00	6	5.00	2.96	4	**14**
2E	3	3.00	3	2.50	3.26	5	**11**
2C	4	4.00	4	4.00	2.90	2	**10**
2D	2	1.50	2	1.00	2.93	3	**6**
2A	2	1.50	3	2.50	2.67	1	**5**

- Theme: Theme numbers were listed in the first column
- No. of Top 5: The number of statements per theme that has a 'x' indicated in the 'Top 5' column.
- Ranked importance: The data were sorted according to the second column in ascending order so that the themes receiving the highest number of 'Top 5' statements (second column) are listed last. The researcher then allocated a rank to each theme (third column) with the least important receiving a rank score of 1 and each theme thereafter receiving an incrementally higher score. Themes that had the same number in the second column received a shared rank in the third column (as seen for theme 2A and 2D in Table 3.5).
- Frequency of statements: The number of statements per theme
- Ranked frequency of statements: The data were sorted according to the fourth column in ascending order so that the themes receiving the highest number of statements per theme (fourth column) are listed last. The researcher then allocated a rank to each theme (fifth column) with the least important receiving a rank score of 1 and each theme thereafter receiving an incrementally higher score. Themes that had the same

number in the fourth column received a shared rank in the fifth column (as seen for theme 2A and 2E in Table 3.5).

- Average: The sixth column is a result of summing all statements' 'averages' (Table 3.4) for each theme and dividing the by number of statements (fourth column).
- Ranked averages: The data were sorted according to the sixth column in ascending order so that the themes receiving the highest average per theme (sixth column) are listed last. The researcher then allocated a rank to each theme (seventh column) with the least important receiving a rank score of 1 and each theme thereafter receiving an incrementally higher score. Themes that had the same number in the fourth column received a shared rank in the fifth column (not applicable for Table 3.5).
- Final rank: The researcher summed the scores of the third, fifth and seventh column (ranked importance, ranked frequency, ranked average) producing a final rank score (eighth column). Final rank scores were arranged in descending order to arrange the themes for that question from most to least significant.

(vi) Step six and seven: Reporting the NGT data

Lastly, the researcher chose to present the data using bar graphs indicating final rank scores (ranked importance, ranked frequency and ranked average depicted by different colours) as shown in the following chapter.

3.7. Ethical Considerations

Ethical clearance was obtained through the University of the Witwatersrand Human Research Ethics Committee (Appendix D) - Certificate no. M130810 - so that the researcher could conduct the study. The specific ethical considerations pertaining to this study were as follows: Permission was granted by the publishers of the MBI (Journal of Clinical Epidemiology) before candidates for the study were contacted (Appendix C). Candidates were invited to participate in the discussion groups through the use of a written information letter pertaining to the purpose of the study, the process of the NGT, the requirements of each therapist and the way in which their information will be used (Appendix E). Participants were informed that participation was entirely voluntary and that they could withdraw from the study at any time without any

negative effect. Consent to participate in the study was gained from the participant before they partook in the group discussion (Appendix F). Each therapist gave informed consent for the NGT to be audio recorded (Appendix G). The recordings were destroyed once the research was completed. Confidentiality was emphasized. The researcher did not make use of any names or identities in the study, using codes instead of names.

It was stated clearly that the participants could withdraw at any point and there would be no implications if they chose to do so.

3.9. Summary

This chapter provided an explanation of the research methodology used to establish the content validity of the MBI in stroke patients in South Africa. The study design, population, data collection, data analysis and ethical considerations were described. Chapter 4 will reveal the findings of the study.

CHAPTER 4

RESULTS

4.1. Introduction to the Results

The following chapter presents the results of the groups. Firstly, the demographics of the sample will be presented. Thereafter, the results of the groups using the NGT will be presented in order of the six questions that were presented to each of the NGT groups, each with a list of the emergent themes and final rank scores.

4.2. Demographics of Subject

4.2.1. Participants: Occupational therapists and physiotherapists

As illustrated in Figure 4.1., the majority of the participants in the study (n=15) were occupational therapists (73.3%), with the remainder being physiotherapists (26.7%). All participants were practicing in the field of adult neurorehabilitation at the time of the study (n=15).

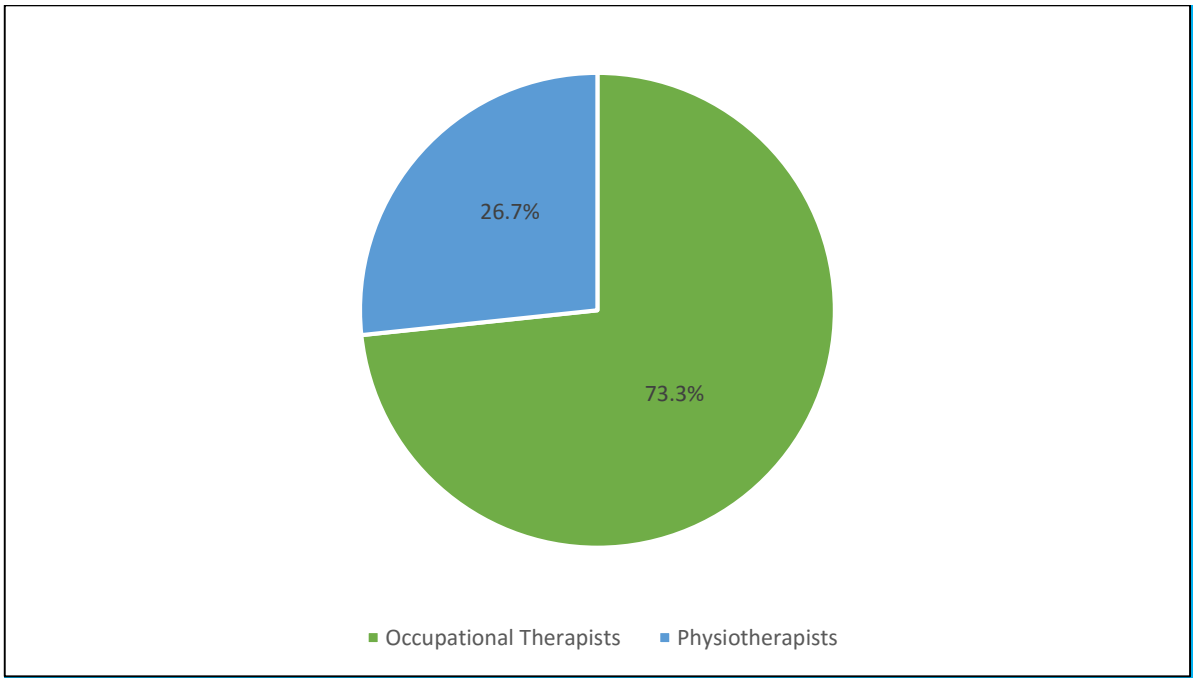


Figure 4.1. Professions of study participants (n=15)

4.2.2. Universities where participants obtained their undergraduate degrees

Eight universities were represented in the study by participants as being the institution of their undergraduate training. Forty percent of participants obtained their degree at the University of the Witwatersrand (WITS) and 13.3% each at Sefako Makgatho University (SMU) and the University of Pretoria (TUKS), as shown in Figure 4.2. a large number of subjects obtained their degree in the Gauteng province (53.3%), i.e. TUKS and WITS, where the study was conducted.

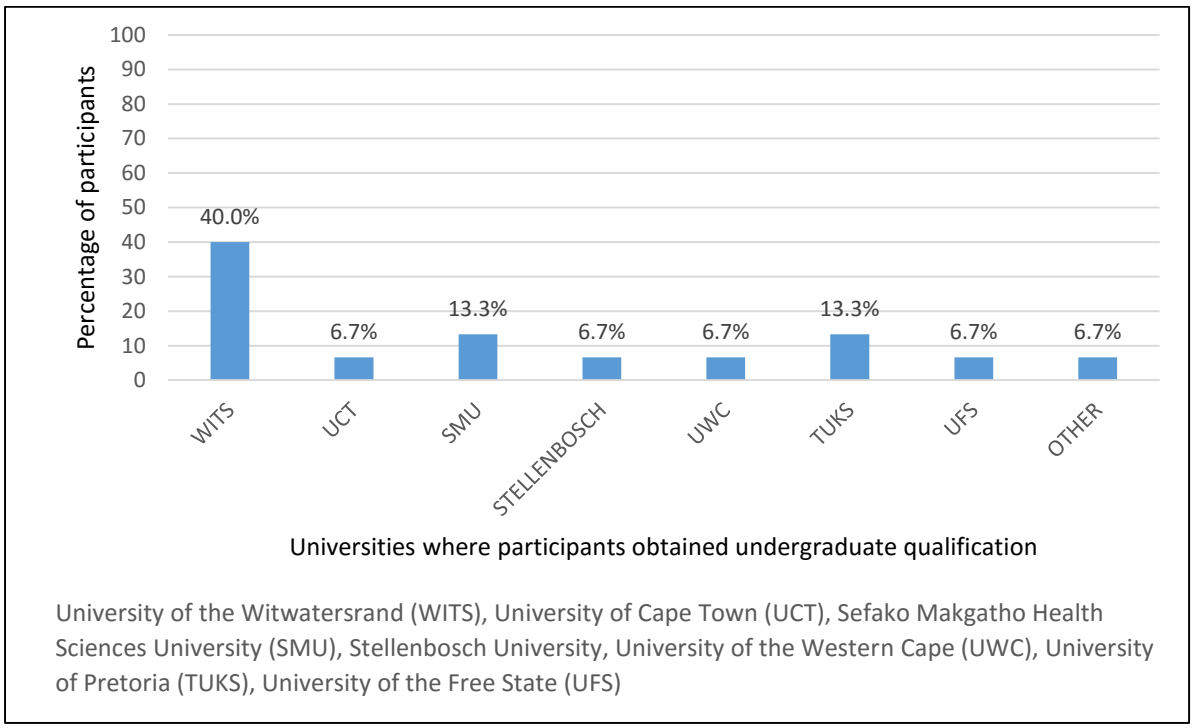


Figure 4.2. Universities where participants obtained their undergraduate degrees (n=15)

4.2.3. Years of experience

From Figure 4.3., the study participants (n=15) had an mean average of 13.7 years and median average of 10 years working experience as occupational therapists and physiotherapists with a range of 4 to 41 years working experience; 53.3%, 33.3% and 13.3% of participants were grouped in the 4-to-10 years, 11-to-20 years, and the more-than-20-years experience groups respectively. In comparison, Figure 4.4. graphs the number of years working experience in the field of neurorehabilitation - the study participants (n=15) had a mean average of 10.1 years and median average of 8 years

experience within a range of 4 – 30 years experience with the largest group of participants in the 4-to-10-years group (73.3%).

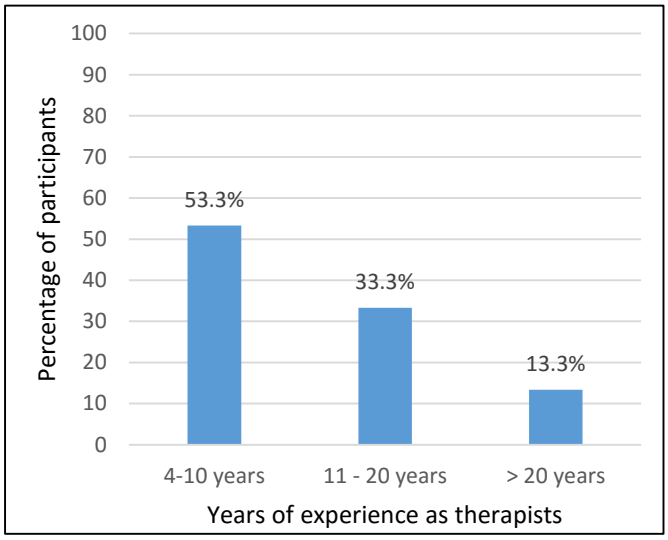


Figure 4.3. Number of years of working experience as a therapist (mean = 13.7 years)

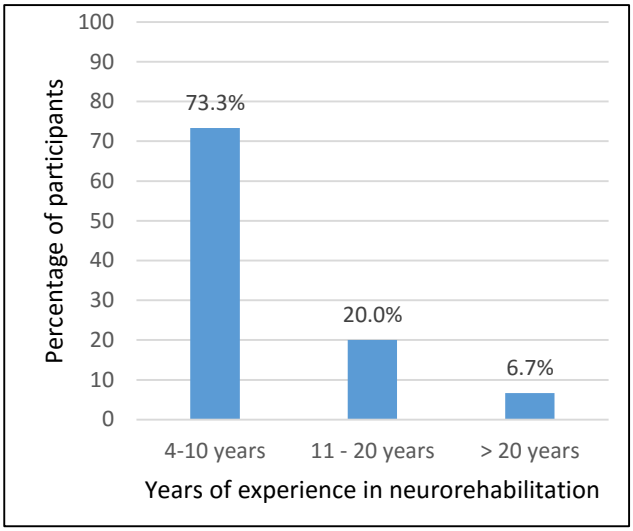


Figure 4.4. Number of years of working experience in the field of neurorehabilitation (mean = 10.1 years)

4.2.4. Undergraduate training in the Barthel Index

Figure 4.5. shows the majority of participants (80.0%) had not received training in any version of the BI on an undergraduate level. Two participants (13.3%) did receive training in the BI and one participant was unsure.

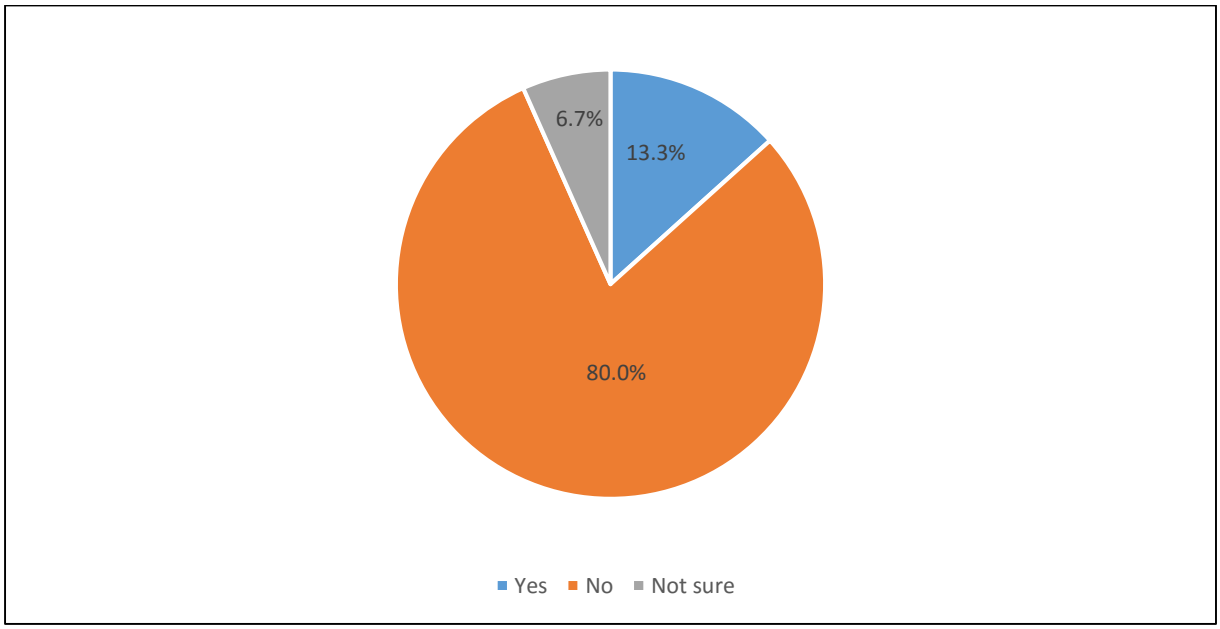


Figure 4.5. Percentage of participants who were trained to use the Barthel Index on an undergraduate level (n=15)

4.2.5. Experience in administering the Barthel Index

Contrastingly, Figure 4.6. shows 73.3% of participants (n=11/15) had experience in administering the BI in the workplace, with the remainder having no or little experience.

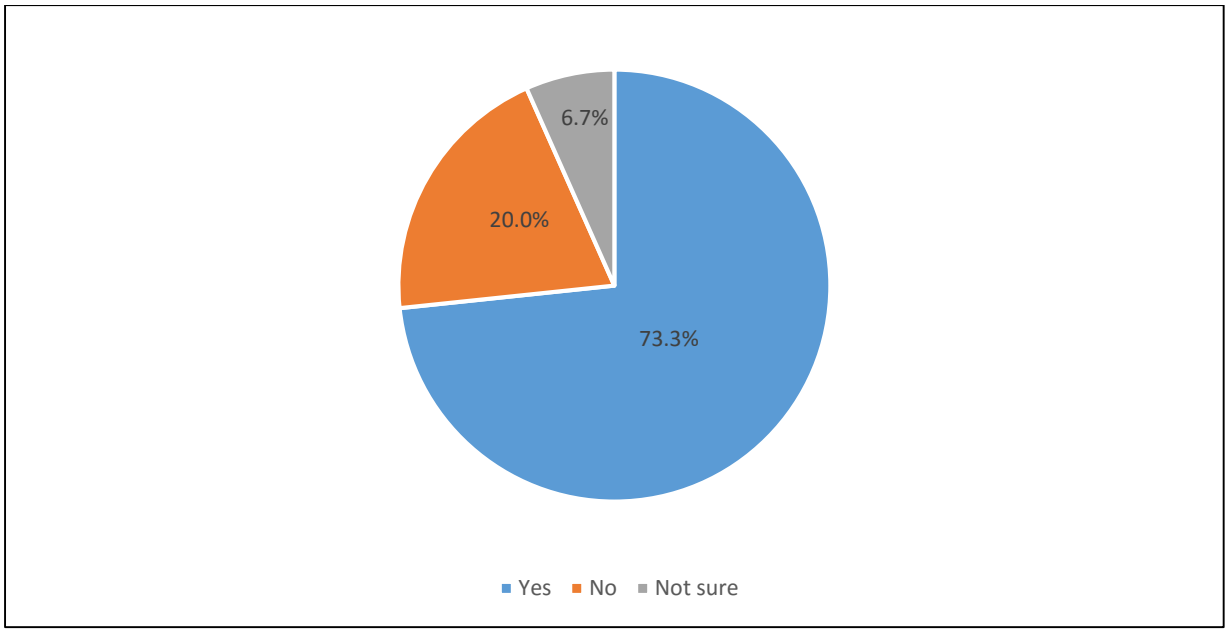


Figure 4.6. Percentage of participants that have administered the Barthel Index (n=15)

4.3. Nominal Group Results

4.3.1. How to interpret results

In the following results, note that *ranked importance* indicates how important the groups regarded that theme and voted that theme most highly, i.e. themes with a high ranked importance means that participants often put these statements high on their voting card and therefore these statements obtained high scores (prioritized from most to least important with highest obtaining a score of 5 and least important a score of 1). Whereas *ranked frequency* indicates how often the theme came up in the idea generation and discussion phases (i.e. theme that generated the most statements), i.e. the number of statements per theme are counted; the more statements per theme- the higher its ranked frequency. *Ranked average* indicates how scores were standardized over the various themes in order to ensure a fair distribution of scores (sum of votes/sum of statements). All bar graphs are ordered according to final rank (highest to lowest final rank scores) and each bar sums ranked importance, ranked frequency and ranked average (refer to colour key) to show its final rank score.

4.3.2. Question 1: Who should administer the Modified Barthel Index?

Five themes arose from the list of 16 statements (Appendix H) generated by the four NGT groups in response to the first question, as listed in Table 4.1 below:

Table 4.1. Themes arising from Question 1: 'Who should administer the Modified Barthel Index?'

Theme and description		Statements from four NGT groups
1A	**Therapists**: Occupational therapists and/or physiotherapists	Occupational therapists, occupational therapy assistants/technicians, and physiotherapists primarily
		If only one - occupational therapists ideally
		Any qualified occupational therapist/physiotherapist (not assistants). Occupational therapists and physiotherapists understand the limitations and understand the language used
1B	**Therapists and nurses**	Occupational therapists, occupational therapy assistants/technicians, physiotherapists and physiotherapy assistants and nurses (trained/stroke unit)
		Rehabilitation team (excluding doctors and including nurses)
		Physiotherapists, occupational therapists and nurses
		Occupational therapist and physiotherapist and speech and language therapist and nursing staff collectively complete different sections because allows discussion to get clear picture
		Occupational therapists, physiotherapists and nurses should be able to complete individually
1C	**MDT**: Therapists, nurses and doctors	MDT should complete as a group
		MDT ideally (Doctor, nurse, physiotherapist, speech therapist)
1D	**MDT and patient and/or caregiver**: Therapists. Nurses, doctors, caregiver and/or patient	Physiotherapist, occupational therapist, nurse, doctor, caregiver and patient [should be able to] individually complete
		Anybody working with neurological patients [should be able to complete the MBI] (therapists, assistants, nurses, caregivers possibly)
		Items are specific enough for everyone to used. Few words may be difficult to understand. Subjective nature of test affects everyone
		Would be beneficial if caregivers/patients could use (language would need to be changed – the patients we deal with will not understand the sentences in the MBI)
1E	**Nurses and doctors**: Nurses and doctors should be able to understand and complete the MBI	Nurses individually
		Nurses and doctors should have general understanding [of how to complete the MBI]

Overall, participants considered therapists (occupational therapists and physiotherapists) and nurses to be the persons who should administer the MBI. The theme 'therapists and nurses' was ranked highest of the five themes in terms of importance and frequency of statements with a final rank score of 14/15 (ranked 5/5 importance, 5/5 frequency of statements, and 4/5 ranked average). The second highest ranked theme (final rank 11/15) suggested that the MDT (i.e. the doctor, nurse and therapists) and patient/caregiver should complete the MBI together

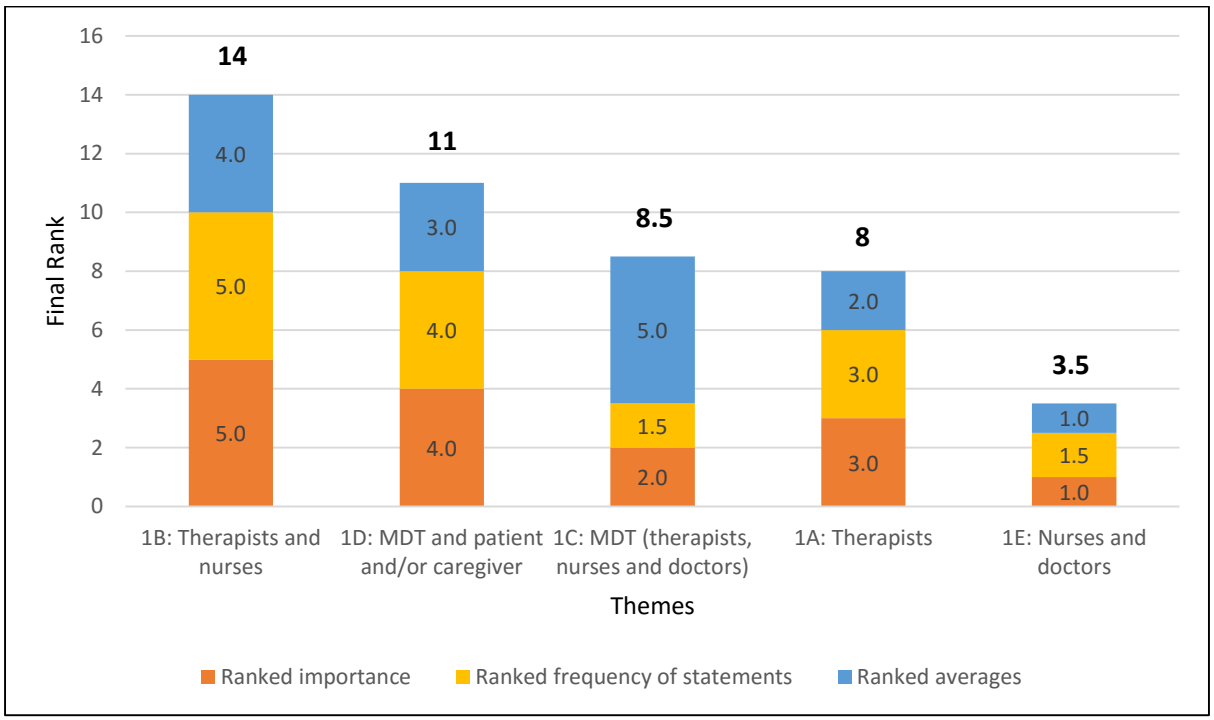


Figure 4.7. Themes arising from Question 1: 'Who should administer the Modified Barthel Index?', ordered according to final rank

4.3.3. Question 2: What language should the Modified Barthel Index be in?

Five themes arose from the list of 18 statements (Appendix H) generated by the four NGT groups in response to the second question, as listed in Table 4.2 below:

Table 4.2. Themes arising from Question 2: 'What language should the Modified Barthel Index be in?'

Theme and description		Statements from four NGT groups
2A	**Translate to most common African languages** – Zulu and/or Sotho	The most common African language - Zulu
		Zulu and Sotho because that is the most popular African language in Johannesburg
		Maybe Zulu because the majority of patients are Zulu
2B	**English since HCWs practice in English**: Since healthcare workers administer the BI, the BI should remain in English since it is the primary language of communication in training and in hospitals.	English because most HCWs are trained in English
		If completed in a group [of HCWs], we can overcome the language barrier
		English because it is administered by therapists who can understand English and [the MBI] does not need patient's understanding (observation)
		English because of hospital policy (all communication is in English)
		English because HCWs are using observation [to complete the MBI], not asking [the patient]
		English because HCWs are trained in English in SA – keeps it standard
2C	**The general population of SA has an understanding of simple spoken English**: It is the medium of instruction at most schools and is most people's 2nd language.	Simple English so that second language persons can complete, although would need to be revalidated
		Use English unless they (patient) can't read and write
		English because everyone has a general understanding
		English version is most needed because it is the medium of instruction at schools and people tend to prefer the English version. Patients and caregivers tend to understand spoken English

Theme and description		Direct statements from four NGT groups
2D	**The MBI should *not* be translated**: By translating a tool, this creates problem of misunderstanding and the tool would need to be revalidated. Rather use a translator to assist or use a different tool.	Shouldn't be able to be translated. However may be difficult for administrator – would become more self-administering if translated – rather use translator to assist
		Shouldn't be translated as all HCWs should be able to understand, and words get lost in translation
2E	**Translate MBI into all SA languages**: Languages vary throughout SA [11 official languages] and by translating the MBI it would be used more widely. Ideal to be available in administrator's home language	If unable to understand English then they need to have it translated
		Should be able to be available in other languages but shouldn't change content and therefore can be used more widely
		Language depends on area – varies throughout South Africa ([translate] into all 11 languages)

As graphed in Figure 4.8., theme 2B was ranked highest overall with a final rank score of 14/15 (ranked 5/5 importance, 5/5 frequency of statements, and 4/5 average) indicating that participants agreed that the MBI should remain in English since HCWs typically administer the MBI and it is the medium of communication in training and hospitals in South Africa. The second overall theme (final rank 10.50/15) indicated that the MBI should be translated into all 11 official South African languages.

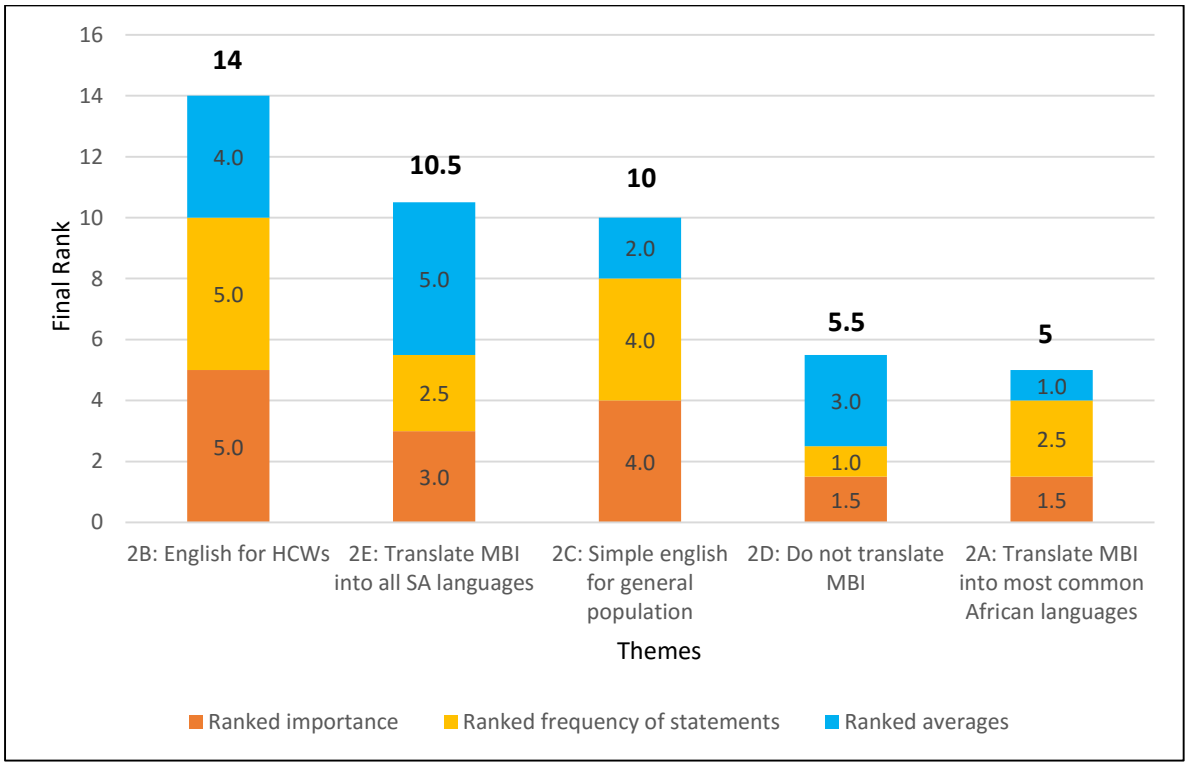


Figure 4.8. Themes arising from Question 2: 'What language should the Modified Barthel Index be in?', ordered according to final rank

4.3.4. Question 3: How can we rephrase the Modified Barthel Index to make it more clear and understandable?

Six themes arose from the list of 22 statements (Appendix H) generated by the four NGT groups in response to the third question, as listed in Table 4.3 below:

Table 4.3. Themes arising from Question 3: 'How can we rephrase the Modified Barthel Index to make it more clear and understandable?'

Theme and description		Direct statements from four NGT groups
3A	**Quantify amount or types of assistance that must be given**: Use percentages or indicate how many people are needed to help and whether verbal or physical assistance is required.	Words should be quantified as some words are vague (e.g. appropriate, some, some degree, minimal)
		Should be more clear ([MBI is] vague) – specify/quantify how much assistance or how often (e.g. using percentages as words like minimum/moderate/maximum may be vague)
		Clarify "maximum" and "moderate' and "minimum" – quantify. Use "1 person" or "2 person" etc. Be more consistent throughout items. Percentages also could be used to quantify these words – a key/description should of percentages should be provided on document.
		MBI doesn't make a distinction between (or use of) verbal and physical assistance
3B	**Use simple contextually relevant words or explanations**: Improve understanding of words by substituting difficult terminology with more common/simple words, and/or providing definitions of words because English is many people's 2nd language. Content must be familiar and contextually relevant to South Africans.	Could include explanations of key words (e.g. assistance, supervision, dependence, wheelchair ambulation)
		Words can be changed to more simple words without changing their meaning although [the MBI] would have to be revalidated (e.g. 'ambulation' can be 'walking' or 'ascend' and 'descend' can be 'up' and 'down' etc..)
		Should be phrased in simpler and more descriptive terms ([the MBI] was written for professionals as it uses long words)
		Some HCWs do not have English as 1st language [therefore the MBI should use simple words]
		If all MDT involved [i.e. if all HCWs should be able to complete the MBI] - use laymans terms (e.g. "attendance" not clear) as [current] terms may not be familiar
		Should be clear and simple overall – some items are difficult to understand (e.g. use 'people' instead of 'attendants')

Theme and description		Statements from four NGT groups
		Substitute words that are more common: Propel – push Terrain – ground Attendant – helper Assistance – help Ascend – going up Descend – going down Kerb – raised path near side of road or pavement Or define [words] in definition sheet: Ambulation – 'moving' or 'walking' or 'using a wheelchair Walkerette – rather use walking frame (or needs to be investigated) Incontinence – rather use description (not able to control bowel and has accidents)
		Definition sheet with MBI ([have an] appendix) to refer to with words that need to be described. Some words need to be made more simple or defined in definition sheet (e.g. bowel and bladder)
		Use a simpler terms e.g. "up" for ascend and "short distance"
		Some words should be more contextually relevant (e.g. types of walking aids we use)
		Some terms are not familiar (e.g. walkerette) - this will make a difference if different materials used
		Have more range with regard to what kind of clothing is used in dressing [contextually relevant items]
3C	**Improve understanding of words through translation** into other languages	Some words are not a terminology problem but an English problem. If the words are translated into their language they might understand it better
3D	**Be more consistent** throughout wording/phrasing of MBI	Overall the MBI needs to be more consistent

Theme and description		Statements from four NGT groups
3E	**Do not translate** into other languages	Some words may be hard to translate (not exact words [available for direct translation] or misunderstanding [may occur])
3F	Improve understanding of tasks/ MBI items by **detailing task or breaking up into specific sections/steps**	Phrasing should be more descriptive if patient needs assistance to set-up (e.g. must something be brought?) – [describe] how must it be set-up exactly
		Be more specific with regard to upper body/ lower body dressing
		If there is a profession-specific item rather break it up into steps so that the terminology is understood (by the specific HCW)

As illustrated in Figure 4.9., theme 3B – 'Use simple contextually relevant words or explanations'- obtained the highest rankings in importance (ranked 6/6) and frequency of statements (ranked 6/6) with a final rank score of 15/18. These suggestions of possible substitutions for difficult words were suggested by participants:

Table 4.4. Suggested word substitutions by participants

Current word used in MBI	Suggested alternative for MBI
Propel	Push
Terrain	Ground
Attendant	Helper/person
Assistance	Help
Ascend	Going up
Descend	Going down
Ambulate	Walk
Incontinence	Description: Unable to control bowel/bladder – makes accidents

However, the overall highest ranked theme was theme 3A – 'Quantify amount or type of assistance' with a final rank score of 16/18 (ranked 5/6 importance, 5/6 frequency of statements, and 6/6 average). The statements contributing to this theme emphasized the importance of quantifying the amount of assistance given to the patient using percentages. One statement suggested including a key on the document to improve the reliability of what is understood by words such as 'minimum', 'moderate' and 'maximum' assistance, which was frequently raised in the groups and often compared to what is used in the FIM/FAM. The researcher compiled the following table to illustrate what could be used, based on the words participants suggested and percentages used in the FIM/FAM (simplified):

Table 4.5. Suggested key for quantifying words/amount of assistance in MBI

Word suggested	Percentage
Minimum assistance	Patient contributes 75% or more to task
Moderate assistance	Patient contributes 50% - 74% to task
Maximum assistance	Patient contributes 25% or less to task

Participants indicated that theme 3E – 'Do not translate the MBI' – was the least significant theme (final rank 4/18), in comparison, the theme suggesting translation (3C) ranked fourth overall (final rank 9/18).

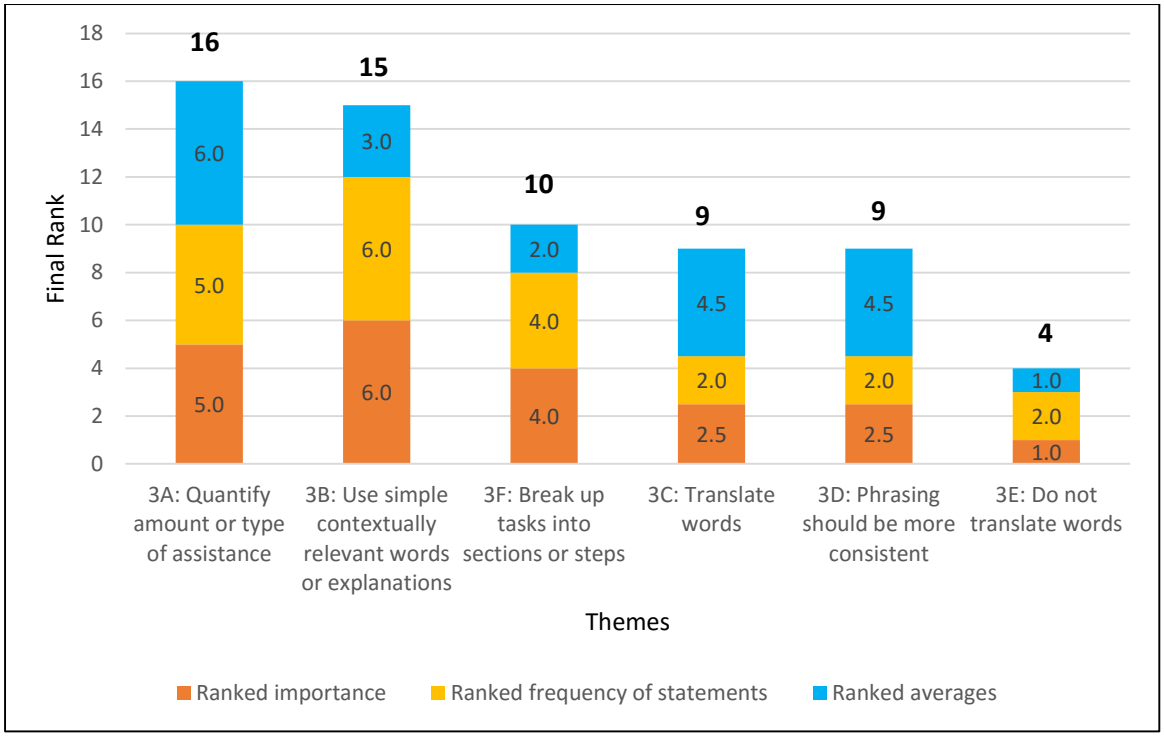


Figure 4.9. Themes arising from Question 3: 'How can we rephrase the Modified Barthel Index to make it more clear/understandable?', ordered according to final rank

4.3.5. Question 4: Compare the Practice Framework to the Modified Barthel Index. Are there any items of the Modified Barthel Index you would include/exclude?

Twelve themes arose from the list of 34 statements (Appendix H) generated by the four NGT groups in response to the fourth question, as listed in Table 4.6. below:

Table 4.6. Themes arising from Question 4: 'Compare the Practice Framework to the Modified Barthel Index. Are there any items of the Modified Barthel Index you would include/exclude?'

Theme and description		Statements from four NGT groups
4A	**Sexual activity is a debatable item to be included**: A relevant ADL, but may be difficult to obtain information regarding functioning or may not be applicable to some patients	Sexual activity relevant but may be difficult to gain information
		Include sexual activity – often left out but vital to patient and important [but] may not be applicable to some patients
		Include sexual activity if it is used as comprehensive assessment (in a rehab unit)
4B	**Include 'Eating'** item from OTPFIII in MBI	Eating not in MBI – should be included – should be distinguished from feeding
4C	**Split 'Dressing' item** in MBI between upper body (UB) and lower body (LB) dressing because difficulty levels differ	Should split upper body and lower body dressing item because different difficulty levels
		Distinguish upper body and lower body dressing as in FIM/FAM because patients function differently in these
4D	**Include 'Personal device care'** item from OTPFIII in MBI	Personal device care should be included in MBI
		Personal device care should be included – [can they] look after wheelchair and assistive devices (e.g. splints)
		Include personal device care if it is used as comprehensive assessment (in a rehab unit)

Theme and description		Statements from four NGT groups
4E	**Revise 'Bathing' item in MBI**: Content is biased toward a western/urban context (e.g. must include fetching water where relevant)	In MBI bathing [item] should be called "washing yourself"
		Bathing item biased to urban – terminology – western terminology – biased
		Bathing [item in MBI] should include fetch water and empty bathtub
4F	**Revise 'Personal hygiene' item in MBI**: Include fetching items (women)	Personal hygiene [item in MBI] should include retrieving items (women)
4G	**Revise 'Feeding' item in MBI**: Include fetching food	Feeding [item in MBI] should include retrieving food to score full independence
4H	**Revise functional mobility items in MBI**: MBI must encompass all aspects of functional mobility, namely; in-bed mobility, transfers (chair-bed, toilet, car/taxi, etc.), walking/running and stair climbing (e.g include in-bed mobility, or group transfers or functional mobility items)	Include in-bed mobility as an item because it tells us if patient has trunk control problems/balance
		Combine transfers with sub-heading (chair-bed, toilet, car/taxi) – transfers require similar movements
		Use functional mobility with sub-headings (walking, wheelchair and stair climbing)
		Include running under functional mobility
		Include bed mobility as an item
4I	**Revise 'Toilet' item in MBI:** Incomplete/incorrect. Item is 'toilet transfer' (On and off the toilet) but includes 'toilet hygiene' tasks. Not every score includes the patient's level of independence in dressing and cleaning their body.	In MBI toilet transfer is not correct (includes toilet hygiene)
		Toilet hygiene does not include dressing and cleaning body– important
4J	**Revise 'Bowel control' and 'Bladder control' items in MBI**: Include management	Bowel and bladder control – should include management

Theme and description		Statements from four NGT groups
4K	**Uncategorized**: Irrelevant statements - do not answer the question posed to the group	Barthel can be used widely since it is free and accessible and should therefore be more specific
		Generalizing in MBI can be misinterpreted
		Items should be re-ordered from most to least difficult
		Participation in hospital does not reflect their participation at home
		If we don't add items it might not come up in Rx programme if used as sole ADL assessment
4L	**No changes to be made**: Statement alludes to aspects/items of the MBI that should remain as is (i.e. should not be changed)	Bowel and bladder separate is good – as one may differentiate from other and treated/recovers differently [no changes to be made]
		Stair climbing not particularly relevant to SA – but due to change – should be retained in MBI [no changes to be made]
		Functional mobility better described in MBI – separate items [no changes to be made]
		I wouldn't add anything more because MBI should be quick and easy (rather use another tool) – would be too long and if used by other HCWs – we may lose them in jargon [no changes to be made]
		Eating is profession-specific (speech therapists) and therefore shouldn't be on MBI [no changes to be made]
		Nice that mobility is broken up into sections (e.g. walking+ wheelchair mobility) [no changes to be made]
		Nothing needs to be excluded [no changes to be made]

As shown in Figure 4.10. below, the theme grouping 'uncategorized/irrelevant statements' received the highest final rank score overall (34.5/36), with the contributing highest ranked importance and ranked average scores. Participants throughout the four NGT groups generated and ranked irrelevant statements more highly than those that were relevant to the question. The statements that were grouped under this theme pertained mostly to the phrasing/language of the tool or were commenting on the MBI as a whole, for example "generalizing in MBI can be misinterpreted", "…[BI] should be therefore more specific", or "items should be re-ordered…". These statements will be explored in the discussion chapter in order to understand the weight of the participant's concerns. However, the second, third and fourth highest ranked themes were themes 4H 'functional mobility' (final rank 31.5/36), 4A 'sexual activity' (final rank 27/36), and 4D 'personal device care' (final rank 23.5/36) respectively. The theme with the highest ranked frequency of statements is theme 4L which grouped statements that referred to aspects of the MBI that should not be changed.

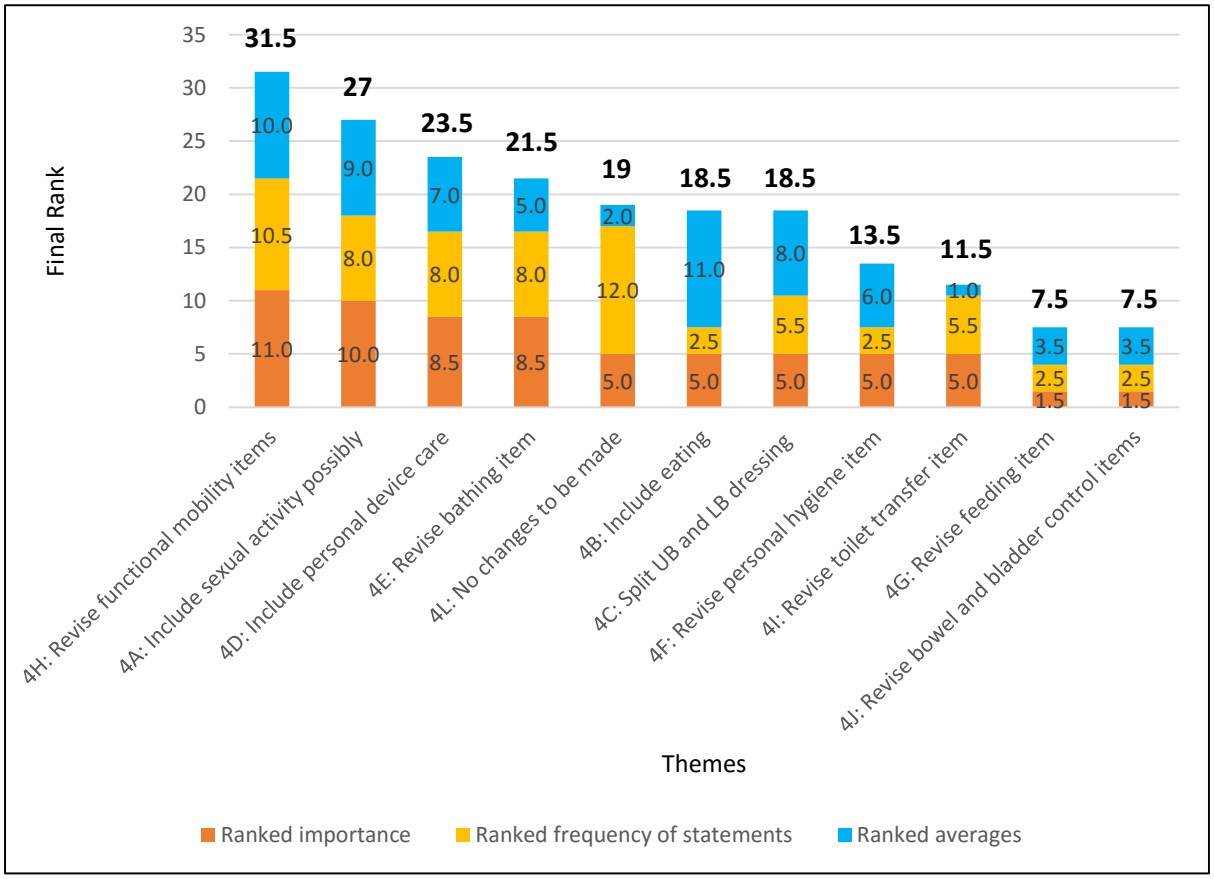


Figure 4.10. Themes arising from Question 4: 'Are there any items of the Modified Barthel Index you would include/exclude?', ordered according to final rank

4.3.6. Question 5: How does South African activities of daily living differ from western activities of daily living?

Seven themes arose from a list of 32 statements (Appendix H) generated by the four NGT groups in response to the fifth question, as listed in Table 4.7 below:

Table 4.7. Themes arising from Question 5: How does South African activities of daily living differ from western activities of daily living?

Theme and description		Statements from four NGT groups
5A	**Accessibility barriers**: Differences in natural (rough terrain) and man-made environment (space, accessibility, toilets outside, no fixtures) make ADL more difficult. This is linked to socio-economic status – persons with higher SES have a more 'western' home environment	Environment causes limitation to function (space. fixtures. distance. accessible terrain) – MBI assumes this
		Toileting transfer is more complicated (outside)
		Ambulation and wheelchair use difficult due to rough terrain and constrained spaces
		Environments are less limiting in western countries (accessibility. home adaptations) – not case in SA
		Wheelchair ambulation: we don't have access to even terrain – consider rough terrain – difficult and wheelchair breaks
		Most problems are related to socio-economic status and environmental barriers (terrain. accessibility of buildings and transport) – negatively affects ADLs on a large scale
		Location of ADLs differ (bathroom vs. room). Terrain outside house (rough terrain) and space and no lifts – these affect mobility

Theme and description		Statements from four NGT groups
5B	**Resource barriers**: Some ADL require more steps/tasks and time due to poor availability of resources in SA (fetch water, fetch wood instead of using electricity). This is linked to one's socio-economic status – persons with higher SES have greater availability of resources (more 'western')	Environment causes limitation to function (running water. electricity) – MBI assumes this [i.e. MBI assumes a specific environment]
		Water is collected from communal taps with container
		Bathing [item in MBI] doesn't include collecting water
		Environments are less limiting in western countries (running water. electricity) – not case in South Africa
		Fetch water in South Africa compared to those who have a tap
		Electricity a limiting factor. [Some South Africans] fetch wood to prepare food
		[Poor] availability of resources (electricity. water) e.g. often have to fetch water for bathing and toilet is often outside and often a pit toilet
		Transfers in South Africa are different (taxi and floor for sleeping)
5C	**Lack of education or knowledge** about condition/rehabilitation/assistive devices affects adherence which affects overall recovery and functioning in ADL. e.g. a patient with a poor understanding of his/her condition and the purpose and importance of the splint or wearing regime results in poor compliance or application, and ultimately, poor functioning. Westerners may therefore incorporate the use of assistive devices that facilitate independence more in their ADL than South Africans.	Due to lack of education or knowledge – [some South Africans] believe in witchcraft and will therefore seek help from traditional healers
		Lack of knowledge about assistive devices (e.g. splints) affects their use of it. resulting in impaired functioning and poor attitude toward assistive devices affects their use of it resulting in impaired functioning

Theme and description		Statements from four NGT groups
5D	**Poor availability of resources for rehabilitation** (e.g. rehabilitation services, ADL assistive devices) in South Africa due to financial constraints or limitations against foreigners negatively affects functioning in ADL	Far more access to resources available in western countries (would score higher in MBI) – assistive devices are free in some countries
		Financial constraints in South Africa
		Affordability and accessibility of assistive devices (e.g. ideal assistive devices not available)– limiting [factor against functioning]
		More pressure in hospitals (staff shortages and bed occupancy) – less time in rehab – negatively affects ADL [performance]
		Lack of assistive devices in South Africa often – affects functioning
5E	**Culture habits and routines** in South African cultures provides a diversity of ADL etiquette/methods/positions (e.g. feeding with hands, clothing differences)	Feeding often hands are used/are appropriate
		Bathing differs to culture/class (e.g. basin. bath) – basin bath is norm in SA
		Should look at how patient was doing ADL premorbidly
		Different etiquette in most ADLs
		Feeding is normal to eat with hands instead of fork and knife in some groups – culture
		Majority female patients in government hospital don't wear pants - wear skirts
		Diversity of cultures in health setting (clothes. feeding. toileting differences)
5F	**Learnt helplessness**: Wives do more for patient as a sign of respect as part of their culture which affects patient's recovery/ functioning in ADL	In our culture families are "enablers" and tend to help patients more, especially male patients have a role to be taken care of. Female patients being cared for by female caregivers are "overcared"
5G	**Uncategorized/irrelevant:** Irrelevant statements - do not answer the question posed to the group	Patient may score well in hospital in MBI – different to home
		[According to a study] South African patients were less functional on discharge compared to admission to western countries – South African patients are less functional

As reflected in Figure 4.11., two themes were awarded a considerably higher final ranking compared to other themes; theme 5B – 'resource barriers' – and theme 5A – 'accessibility barriers' – scored 19/21 and 18.5/21 respectively, with the 'resource barriers' theme having the highest ranked importance and frequency of statements, and the 'accessibility barriers' theme having the highest ranked average. The 'resource barriers' theme emphasizes that some ADL in SA require more steps and time due to poor availability of resources in SA and the 'accessibility barriers' theme encompasses statements that highlight the challenges of the South African natural environment and man-made environment which makes ADL more difficult. Both themes acknowledge that these barriers are linked to socio-economic status and that persons in more high income homes usually have a more western home environment and access to water and electricity.

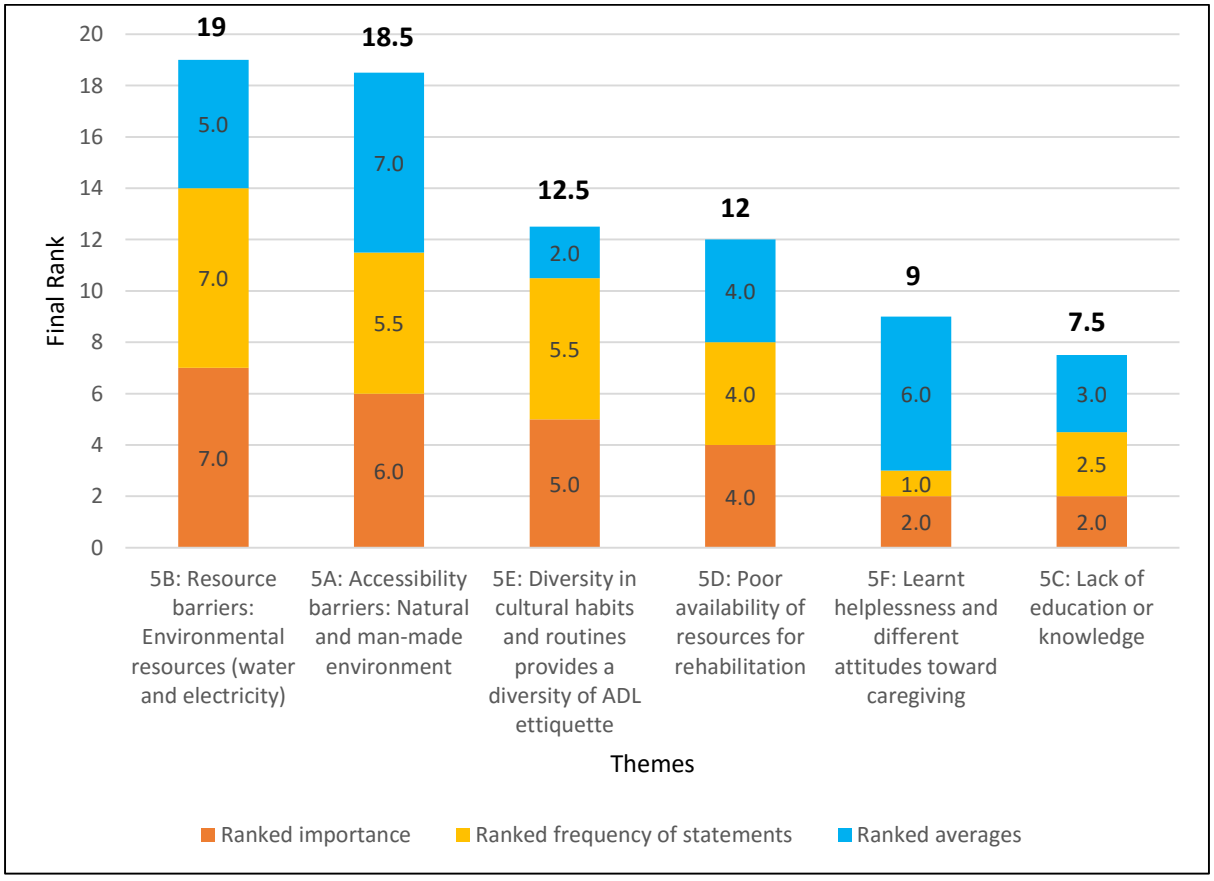


Figure 4.11. Themes arising from Question 5: 'How does South African activities of daily living differ from western activities of daily living?', ordered according to final rank

4.4. Conclusion

The demographics of the participants involved in the study and the findings from the four NGT groups investigating the content validity of the MBI in stroke patients in South Africa were reported in this chapter. A discussion of these results will be presented in the next chapter.

CHAPTER 5
DISCUSSION

5.1. Introduction

The following chapter aims to discuss the results presented in the previous chapter. Firstly, the sample characteristics will be discussed so that the results are interpreted in context. Secondly, two of the three research objectives are answered, namely (i) whether all ADL items included in the MBI reflect current ADL theories and frameworks, (ii) the appropriateness of the content of the MBI for the South African population. Lastly, the limitations for the study and recommendations for future studies are listed.

5.2. Demographics of subjects

The study comprised of 15 therapists working in the field of adult neurorehabilitation in Gauteng, South Africa. As shown in the results, the majority of the participants were occupational therapists (73.3%), with the remainder being physiotherapists. The large percentage of occupational therapists can be accounted for by the sampling method used - the snowball sampling method - since most experienced therapists (including the researcher) are more likely to know other experienced therapists within the same profession. Nevertheless, the occupational therapy participants assisted in answering the study objectives as they gave the study a comprehensive understanding of the self-care practices of South Africans, since ADL functioning is an occupational therapist's primary focus in acute neurorehabilitation. However, more physiotherapists could have provided more detail on the aspects of mobility in the MBI, since mobility and gait retraining are large aspects of their workload. It is recommended that future studies which aim to change or develop an ADL outcome measure use physiotherapists to contribute on mobility items.

The study sample was diverse in terms of their place of undergraduate training since all eight training institutions across South Africa were represented. The

province producing the highest number of undergraduates for the sample was Gauteng (43.3%), this was expected since all participants were working in Gauteng at the time of data collection.

The sample for this study had an average of 13.7 years working experience per therapist, and an average of 10.1 years working experience in the field of neurorehabilitation per therapist; emphasizing the sample's expertise and knowledge regarding the ADL functioning of South African stroke survivors in rehabilitation. Approximately half of the sample had more than 10 years experience as a therapist (46.6%), and the other half having 10 years experience or less (53.3%). This afforded the researcher a sample that is a balanced representation of the population; with the younger therapists typically working in government hospitals, and the most experienced therapists working in academic institutions or private practice settings – ensuring experiences of stroke survivors from a variety of settings were represented.

The majority of participants (80.0%) had not received formal training in administering the BI at an undergraduate level. However students may still be exposed to the BI informally during their practice learning placements even if it is not covered in the curriculum. This finding is supported by a South African study that found that only one of seven occupational therapy training institutions in South Africa include the BI in their curriculum (7). Although most therapists are not introduced to the BI on an undergraduate level, the majority of participants (73.3%) indicated that they had administered the BI at least once in practice. However, a recent study reported that the majority of South African occupational therapists reported that they 'never' or 'rarely' (65.52%) use it frequently in practice, and prefer using general observations for assessment (7). Overall, South African therapists are not trained in the BI as students, nor are required to use the BI once practicing. This is a concerning finding since functional rehabilitation is the specialty of occupational therapists and valid, reliable outcome measures should be the first-line assessment method as opposed to subjective findings. Furthermore, the profession is missing an opportunity for gathering evidence for practice. It is recommended that South African universities include the BI in their curriculum in order to encourage an

EBP approach in student practice in order to cultivate naturally scientific-minded therapists. Training in the use of the BI is also recommended by the literature to improve the inter-rater reliability of the tool (50,51).

5.3. Objective 1: Are all Activities of Daily Living items included in the Modified Barthel Index according to current Activities of Daily Living theories and frameworks?

The first objective aimed to determine whether the MBI (1985) accurately reflects current ADL theory and frameworks used, specifically the OTPFIII and ICF.

As summarized in the literature review (see 2.7.10.), four of the nine tasks that form the framework for ADL in the OTPFIII are not included in the MBI. Namely eating, personal device care, sexual activity and aspects of functional mobility. Throughout the four NGT groups, all of these items were suggested to be included in the MBI. Of these four ADL, functional mobility was ranked highest, followed by sexual activity, personal device care and lastly, eating.

Currently, the MBI includes four aspects of functional mobility in the tool as separate items, namely chair/bed transfers, toilet transfers, walking or wheelchair mobility, and stair-climbing. The theme suggesting revision of functional mobility items highlighted that the MBI should encompass *all* aspects of functional mobility According to the OTPFIII this would include in-bed mobility, wheelchair mobility, transfers, ambulation and carrying of objects in order to accurately and comprehensively reflect the patient's performance in this area. The statements receiving the highest ranked votes for this theme were statements pertaining to the inclusion of 'in-bed mobility' as an item, confirming in-bed mobility as an important and common rehabilitation goal in acute stroke rehabilitation. Moving around independently is the key to one's functional independence in everyday tasks from getting up in the morning, running errands and accessing the community – mobility is the backbone to independence in many tasks. The devastating consequences of stroke often renders one immobile due to weakness, joint instability, gait pattern deficits and additional sensory and perceptual abnormalities which impairs one's ability to

mobilize effectively. Even once these impairments are resolved and the patient is able to mobilize in the hospital setting, this is just the start of stroke patient's recovery in the South African context. This study highlighted that when you consider the accessibility barriers in the community, mobilizing becomes more challenging and time-consuming compared to western environments. Specifically, rough terrain, space limitations, poor accessibility, far distances to toilets and a lack of housing fixtures makes this ADL more physically demanding. It is recommended that all aspects of functional mobility should be included in the MBI in order to improve its content validity. Furthermore, the content description of the items should accommodate for aspects of the South African environment that affects mobility to improve the validity and sensitivity of the tool. For example, by separating walking over smooth surface/indoors and walking over uneven surface/outdoors - and scoring each separately - this would improve sensitivity of the tool by being able to score the client's skill appropriately and lessen the MBI's ceiling effect.

Secondly, statements contributing to the sexual activity item was ranked third highest in the fourth question posed to the groups – suggesting that it should be considered for inclusion in the MBI. All statements contributing to this theme identified that sexual activity may not be applicable to some patients and would be difficult to gain information regarding functioning in this area. Since the BI is most commonly administered through observation by the HCW – particularly in the hospital– it would not be possible to obtain an accurate score for this item. However, the literature recognizes sexual activity as an important, but frequently overlooked aspect in neurorehabilitation. Therefore, one must be aware that results may be biased by therapists in this study's NGT groups since the literature has identified that therapists are reluctant to approach this subject and therefore neglect it in therapy (61). With regard to its appropriateness for the South African context, it has been found that South African patients in both urban and rural settings find this item culturally inappropriate (35). But it needs to be considered that younger people are having strokes and therefore sexual activity as an item may be become increasingly relevant and applicable to the South African stroke population. It is clear that this item remains a controversial topic and it is recommended that future studies investigate the opinions of

South African stroke survivors to determine whether this is a need in their rehabilitation.

Thirdly, ‘Include personal device care’ was ranked the fourth highest theme in the fourth question posed to the groups. Similarly to sexual activity, personal device care is a debatable item to be included in the MBI as it may not be applicable to all patients (not all stroke patients own assistive devices). Furthermore, there is a multitude of varying types and models of assistive devices and therefore scoring for this item would be difficult and possibly unreliable. On the other hand, personal device care is not well supported by the South African healthcare system and therefore most patients are responsible for the care and maintenance of their devices (55), making it a relevant ADL for the South African context. It is recommended that future studies investigate the opinions of South African stroke survivors to determine whether this is a need in their rehabilitation.

Lastly, ‘Include eating (swallowing)’ was ranked the least important theme amongst the four ‘missing’ ADLs from the MBI. ‘Include eating (swallowing)’ was ranked lower than theme 4L which consisted of statements suggesting that the MBI should not be changed. Therefore collectively, participants felt it was more important for the MBI to remain as is than the suggestion to include ‘eating (swallowing)’ as an item. In the discussions throughout the four NGT groups, participants voiced concern that speech and language therapists typically perform swallow assessments which requires training. Therefore, including it in the MBI would restrict the sample of HCWs that can complete the tool (i.e. a speech therapist would need to be present to assess the eating item and therefore another HCW - such as an occupational therapist – would not be able to complete the tool independently). Additionally, incorrect or inexperienced therapists administering swallow assessments would result in poor inter-rater reliability in the MBI and could result in aspiration pneumonia if a safe swallow is not facilitated in the MBI evaluation since most stroke patients are prone to dysphagia (47). Therefore, it is *not* recommended to include eating as an ADL item in the MBI as it relies on the presence of a speech therapist to perform a

formal swallow assessment, and therefore would no longer serve as an easy-to-administer outcome measure for any HCW.

5.4. Objective 2: Is the content of the Modified Barthel Index appropriate for the South African population?

The discussion for this objective follows the format of the content validity analysis TOS sub-headings (Table 3.2, section II) which formed the methodology of this study and the questions posed in the groups in order to determine whether the content of the MBI is appropriate for the South African population. Each sub-heading integrates the results from this study and the previously discussed literature in order to address all areas of content validity.

5.4.1. Appropriateness of the directions for the instrument

No formal directions are provided to the administrator prior to testing in the original 100-point BI or MBI. Additionally, no training is required for any versions of the BI. This assumes that the outcome measure can be used by anyone and should be understood on first impression. As discussed in the literature review, the use of standardized training of the BI is not compulsory but is encouraged in order to improve reliability (50,51). The most recognized method of certification of training in the use of the BI is costly and requires access to the internet (85), which may not be suitable for the South African context. Therefore, in order to ensure a reliable understanding of a tool on first impression, the MBI's item descriptions need to be in a language understood by the administrator and the wording must be concise, clear, and complete to avoid ambiguity or confusion. For this reason, the BI has been translated into various languages for non-English-speaking nations (3–5,30) and revision of ambiguous items has been suggested (3,32).

In order to determine the appropriateness of the directions/instructions for the instrument, the researcher's first question to each of the NGT groups in this study was "Who should administer the MBI?". This question aimed to orientate the participants and reach a consensus as to whom the tool should be designed for – since the language of a tool is largely dependent on who will be administering it. For example, a tool such as the FIM/FAM's intended use by

trained HCWs, uses mostly jargon, compared to a tool such as the Stroke Impact Scale, intended as a self-administrating questionnaire for use by stroke patients, which uses simple everyday words. In this study, participants voted therapists (occupational therapists and physiotherapists) and nurses to be the persons who should administer the MBI to South African stroke patients. This finding lends itself to the researcher's second question to the group, "What language should the MBI be in?" as South Africa is a multilingual nation. 'English, since HCWs practice in English' was the highest ranked theme overall. Participants agreed that the MBI should remain in English since it is the medium of communication in all South African hospitals, and since the previous question identified HCWs as the ideal administrators of the tool. The decision for the test to be in English is also practical as translation into all official languages will be costly and time-consuming. Across all four NGT groups in this study, no statements suggesting the need for directions or training in the MBI were raised, and the sample reached a consensus that the test should remain in English. This means that the current language of the MBI (English) is appropriate for the South African population. Further research is needed to determine the effect of training on the inter-rater reliability of the MBI in South Africa. If training is found to improve the inter-rater reliability of the tool, it is recommended that standardized directions or training options that are feasible for the South African population be developed.

5.4.2. Content areas covered

Content validity refers to the extent to which a certain set of items are relevant to and representative of a specific content domain (75).That is to say, for this study, whether the set of items in the MBI are relevant and representative of the ADL of South African stroke patients. The question "How does South African ADL differ from western ADL?" was posed to the four NGT groups in order to establish what differences exist between South African and western ADL to determine the completeness of task descriptions and cultural appropriateness of the MBI.

Themes arising from question 5 gave the researcher a clearer understanding to how the South African context causes variations in ADL tasks in South Africa

versus the western world, influencing the completeness and cultural appropriateness of content areas covered in the MBI. Two themes that strongly emerged were ‘Resource barriers’ and ‘Accessibility barriers’, with respective final rank scores of 19/21 and 18.5/21.

Participants discussed how a lack of resources (access to water and electricity) acts a barrier to some South African’s performance in their ADL. It was found that South African ADL required more steps and time due to poor availability of resources (running water and electricity indoors). For example, westerners pour bathwater from a tap, drain it once complete, and have materials readily available at the bath/shower. However, as emphasized in the literature, this is not the case for approximately half of the population - 44% of poorer South Africans need to fetch water from an outside/ communal tap, carry the water in a bucket or container, and fill a basin or zinc tub/basin in order to bath. Thereafter, the tub or basin must be carried outdoors in order to be emptied. The literature review also identified that the MBI does not include ‘obtaining supplies’ as part of the bathing as described in the OTPFIII, indicating incompleteness of the content of the tool. It is recommended that this be included in the MBI.

Additionally South African ADL are more difficult due to differences in the natural environment and man-made environment (i.e. accessibility barriers). Rough terrain in rural areas, limited and crowded space in homes, toilets built outside and a lack of indoor fixtures (baths, showers, appliances, etc.) make tasks more difficult to complete due to the physical demands needed to overcome environmental barriers such as one requiring better balance when walking over an uneven surface, or increased strength and endurance to walk or push a wheelchair to access an outside toilet. Both themes acknowledge that these barriers are linked to socio-economic status and that persons in more high income homes usually have a more western home environment and access to water and (space, accessibility, toilets outside, no indoor fixtures) electricity. This finding is supported in the aforementioned literature where it was found that approximately 40% of South Africans – specifically the poor - use outdoor government subsidized pit latrines or the bucket system. With such

a large portion of the population relying on these environments, it emphasizes the stark environmental differences between westerners and South Africans and the need for the MBI to not assume as western bias. On this note, Shah et al. (1993) argues that the Barthel "should not be expected to measure influences of culture, religion, architecture or other externally imposed barriers" (86, page 71). But is it not important to reflect the physical ability of the individual in their context? It is of no value to a clinician to score a patient as physically 'fully independent' for an item in an environment that is foreign to him (e.g. only assessing a patient on a western toilet because the tool assumes it) – surely we want a tool that can assess people regardless of the context and not one that can only be used in western environments. It is recommended that each item of the MBI consider all environments and fixtures needed to complete ADL.

5.4.3. Instrument items

In order to determine a tool's content validity; clarity, statement fit (item appropriateness), redundancy and consistency must be inspected (77). Clear and simple wording ensures that the items are easy to understand and make sense (77). Several themes regarding the clarity and contextual appropriateness of the MBI items arose from the discussions and are discussed below.

The third question posed to the group, "How can we rephrase the MBI to make it more clear and understandable?" resulted in theme 'Quantify amount or type of assistance' being ranked highest overall. This theme grouped statements that suggested that in order to improve understanding and clarity in the MBI, the amount of assistance required in each item must consistently be quantified either through percentages (as in the FIM/FAM) or the amount of persons required to assist in the task. The MBI uses a variety of methods in describing assistance, such as using descriptors for instance "minimum/moderate/maximum", or of the number of people required, e.g. "two attendants" or "one person", or where assistance is described relating to objects or parts of the task, e.g. "cut meat, open milk carton, etc.". This varying phrasing was perceived as vague and inconsistent by participants. One participant suggested that a key or description should be provided on the document for the

administrator to refer to. It was recommended that each item description in the MBI referring to assistance must quantify the amount of assistance required as described in Table 4.5. However, this method of quantifying the degree of assistance can still be subjective.

Participants suggested that difficult terminology in the MBI be substituted with more common/simple words, and/or providing definitions of words. This theme was the most discussed and most voted theme across the four NGT groups, emphasizing the urgency participants placed on the need to improve the clarity of the MBI for the South African population. Participants frequently commented that the MBI used complex English words and difficult terminology which may not be appropriate for the South African population since English is many people's second language. This is supported by the literature which illustrated South Africa as a multilingual nation with the large majority of the population having an African language as their mother-tongue. Therefore, although English is the medium of instruction at schools and training institutions for HCWs– it is often a HCW's second language. Participants suggested that the words and phrasing used be substituted with more simple words or explanations to improve clarity and understanding of the test listed in Table 4.4.

Additionally, it was identified in the groups that some words cannot be substituted with single simple words but require a definition such as for the word 'incontinence'. It is therefore recommended that each MBI item's content be perused and complex terminology that cannot be substituted by simpler words are given a longer explanation or a 'definition sheet' be provided as an appendix to the tool as suggested by one participant. Lastly, it was also mentioned that some words used were not contextually relevant or familiar to the South African population, such as 'walkerette'. It is therefore recommended that the item descriptions in the MBI be perused and any contextually unfamiliar words be substituted with South African words or item descriptions, however no descriptions were offered by participants.

5.4.4. Opportunity for revision of items

Collectively over the four NGT groups, all items in the MBI were recommended for revision, however only the items that were recommended for revision from more than one NGT group are discussed below as it ensures overall group consensus and the items most highly voted for revision. Revision and inclusion of functional mobility items have already been discussed (see 5.3.). The following recommendations for each item are listed from highest to lowest priority based on final rank scores for question four "Compare the Practice Framework to the MBI. Are there any items of the MBI you would include/exclude?":

(i) Bathing: Statements contributing this theme recommended rewording and adding steps to the item since the description of the item is biased toward western bathing. Firstly, the item name should be changed from 'bathing self' to 'washing' in order to avoid assumptions in the manner in which one cleans oneself (i.e. using a bath versus a shower). This is supported by the ICF where the same item is called 'washing yourself' (20). Secondly, the item should include fetching and emptying bathwater as this is relevant to rural South Africans. Lastly, the item's wording needs to be revised as it tends to have an urban/western bias, such as the assumption that a bath or shower is used, rather than a zinc tub or basin.

(ii) Dressing: Statements contributing to this theme was proposed by two NGT groups suggested that the dressing item be split into two sections, namely; 'Upper-body dressing' and 'Lower-body dressing' as in the FIM due to the differences in difficulty levels. This is supported by a reliability study of the original BI that suggested splitting the item since this item was found to have the lowest reliability score (32).

5.4.5. Opportunity to recommend deleting an item

An important step in improving the content validity of a tool is removing items that are redundant or irrelevant to the construct you are assessing (76). In this study, no items of the MBI were recommended for deletion compared to other studies that have suggested the bowel and bladder control items be removed from the MBI as these items are regarded as a physiological function rather

than an ADL (2). Rather, revision of these items was suggested by participants - this finding is supported by other studies (3,32).

5.4.6. Opportunity to add additional items to the instrument

This section was answered by the first objective as discussed in 5.3. which posed the question: “Are all ADL items included in the MBI according to current ADL theories and frameworks?”. Four additional items were considered for inclusion in the MBI.

5.4.7. Opportunity for additional comments

As seen in Table 7.8. (Appendix H), theme 4K – ‘Uncategorized/irrelevant statements’ was awarded the highest final rank score for question four. This theme was not included in Figure 4.10. as it pertained to additional comments frequently raised by the group but were ultimately not relevant to answering which items should be included or excluded from the MBI. However, since these statements collectively achieved the highest score for ranked importance, it is essential to discuss the additional comments regarding the MBI since the group emphasized their importance. The statements listed in the results emphasize the following:

(i) The statements “Barthel can be used widely since it is free and accessible and should therefore be more specific” and “Generalizing in MBI can be misinterpreted”: Participants re-emphasized the importance of clear, contextually specific and culturally appropriate wording, supporting the findings discussed above (5.4.3.) in order to ensure the content validity of the MBI for the South African stroke population.

(ii) “Items should be re-ordered from most to least difficult”: This pertains to the scoring of the MBI, suggesting that if items are re-ordered from most to least difficult, this would simply aid the administrator to score the patient in a more logical fashion and shortening the test (e.g. all items below an item scoring “total dependence” would automatically score the lowest). Future research regarding the difficulty index of each item for the South African stroke population is recommended, as performed by Shah et al. (1992) for populations in Australia, UK, USA and Japan (52).

(iii) “Participation in hospital does not reflect their participation at home”: This statement supports the discussion above (see 5.4.2.) arguing against Shah et al’s (1993) reasoning that the Barthel “should not be expected to measure influences of culture, religion, architecture or other externally imposed barriers” (86, page 71). To address this issue, the well-known floor and ceiling effect of the MBI needs to be addressed as it makes the tool less sensitive to patients with minor or severe strokes and in patients that live in impoverished areas. One study illustrated this effect, for example a patient that has suffered a severe stroke will progress in hospital from initially intubated and non-responsive on a nasogastric tube, to extubated and alert and starting to swallow when fed orally, to independent rolling in bed, then independent sitting up in bed and standing but will score 0 on the MBI throughout, despite his/her improvement in ADL (feeding and mobility) (21). Furthermore, due to various items of the MBI lacking steps required for the completion of ADL in the South African context, a patient may score full independence on the MBI in the hospital setting, however the patient will often require assistance at home for that ADL as skills required for some tasks/movements were not assessed and treated (e.g. patients ability to fetch water to bath). It is essential for the neurorehabilitation therapist to accurately assess a patient’s ADL functioning in order to aim for appropriate home reintegration and functional independence, therefore the MBI should accommodate the South African context.

(iv) “If we don’t add items it might not come up in Rx programme if used as sole ADL assessment”’: This statement was made by a participant that motivated that although the NGT groups were suggesting more items to be added to the MBI (see 5.3.) – making an already long tool even longer – it is imperative that the MBI reflects all ADL tasks in the outcome measure to ensure a holistic and comprehensive reflection of a patient’s true performance in the ADL domain. As mentioned in the introduction of this report, one advantage of this is that it provides therapists with insight into the reality of a typical South African’s ADL practices and this would encourage more realistic and appropriate goal-setting for community reintegration.

5.5. Evaluation of the Study

5.5.1. Limitations of the study

The following limitations to the study were identified:

(i) The demographic profile of the group consisted of almost three quarters of participants being occupational therapists due to the sampling method (snowball sampling – therapists tend to know more therapists within their profession). The uneven distribution of occupational therapists and physiotherapists in the groups may create a bias toward occupational-therapy focused themes.

(ii) In the NGT groups, the researcher undertook the role of the group facilitator (asking questions and facilitating discussion) as well as being the scribe; (recording/typing each statement generated) as people listed their statements during the round-robin and as participants added/combined/deleted ideas during the discussion phase. This caused frequent breaks in the discussion in order to record ideas which interrupted the flow of thought and debate, resulting in a possible loss of valuable data in the groups. In future it is recommended that a research assistant is used.

(iii) Demographic data should have been checked for normality.

(iv) The questions posed to the groups: Regarding question 3 - ask jurors to evaluate the extent to which the MBI was clear/understandable *first*, and then whether any changes should be made. Regarding question 4 - the question could have been phrased around the content of the MBI rather than as a comparison. Regarding question 5 – the question could have been phrased to ask *how* people in SA perform their ADLs rather than a comparison

5.5.2. Recommendations for future studies

The following recommendations aim to summarize the gaps identified in the discussion in order to build on existing knowledge for future studies to explore:

- Future studies which aim to change the MBI or develop a new ADL outcome measure, should use a larger sample of physiotherapists to contribute on mobility items.

- Information on the opinions of South African stroke survivors regarding sexual activity and personal device care is needed to determine whether this ADL should be included as an item in the MBI.
- Further research is needed to determine the effect of training on the inter-rater reliability of the MBI in South Africa. If training is found to improve the inter-rater reliability of the tool, standardized directions or training options that are feasible for the South African population should be developed.

Ultimately, following the recommendations of the study listed above (see 5.5.), it is suggested that a future study implementing the abovementioned recommendations be conducted and the new tool be standardized for the South African stroke population.

5.6. Conclusion

This chapter presented the sample characteristics of the study and discussed the findings of the first two study objectives. Firstly, it was found that several ADL items found in current frameworks are not represented in the MBI. Following discussion, mobility items were recommended for inclusion and eating item for exclusion, whilst sexual activity and personal device care require further investigation. Secondly, the appropriateness of the content of the MBI for the South African population was discussed. Most items of the MBI were recommended for revision in order to include all steps and environments encountered in South African ADL. It was also recommended that item descriptions are revised for improved clarity and consistency. No items were recommended for deletion. Lastly, the limitations for the study and recommendations for future studies were listed. The third research objective; (iii) recommendations for adjustments to the MBI for the standardization of the tool for the South African population; will be addressed in the next chapter.

CHAPTER 6

CONCLUSION & RECOMMENDATIONS

The study provides evidence for the content validity of the MBI for stroke patients in South Africa. Despite the scarcity of valid and reliable outcome measures available for the South African population, neurorehabilitation therapists are nevertheless encouraged to use outcome measures that are available worldwide as this encourages therapists to naturally adopt a scientific approach as it guides functional goal-setting and ensures therapists regularly evaluate the effectiveness of their treatment interventions facilitating cost-effective and scientifically guided decisions. The evidence provided in this report contributes to the body of knowledge regarding neurorehabilitation in South Africa, thereby contributing to EBP development in South Africa.

6.1. Objective 3: Recommendations for adjustments to the Modified Barthel Index for the standardization of the tool for the South African population

The following recommendations list summarized the findings from this study and serve as a guideline to future studies that aim to standardize the MBI for the South African stroke population.

(i) Administrators: The MBI should be designed for nurses and therapists (primary administrators of MBI).

(ii) Language: The MBI should remain in English since HCWs practice in English, i.e. the current language of the MBI (English) is appropriate for the South African population.

(iii) Directions/training: South African universities should include the BI in their curriculum in order to encourage an EBP approach in student practice.

(iv) Content: Each item of the MBI should consider all environments and fixtures needed to complete ADL and score the difficulty accordingly.

(v) Instrument items:

- Each item description in the MBI referring to assistance must quantify the amount of assistance required (e.g. amount of task completed by

therapist in percentage; minimum 1 – 24%, moderate 25 - 49%, maximum: 50 – 75%, total assistance: 76 – 100%).

- Each MBI item's content should be perused and complex terminology be substituted by simpler words as suggested above (see 5.4.3).
- Each MBI item's content should be perused and complex terminology that *cannot* be substituted by simpler words are given a longer explanation or a 'definition sheet' be provided as an appendix to the tool.
- Each item's descriptions in the MBI should be perused and any contextually unfamiliar words be substituted with South African words or item descriptions.

(vi) Revision of items:

- The item name should be changed from 'bathing self' to 'washing'.
- The bathing item should include 'obtaining supplies' as part of the task.
- The bathing item should include fetching and emptying bathwater as this is relevant to rural South Africans.
- The bathing item should include zinc tub and basin as options.
- The dressing item should be split into two sections, namely; 'Upper-body dressing' and 'Lower-body dressing'

(vii) Delete: No items of the MBI should be deleted

(x) Additional items to be added to the MBI: All aspects of functional mobility should be included in the MBI and the content description of the functional mobility items should accommodate aspects of the South African environment that affects mobility (e.g. ability to walk over rough terrain) to improve the validity and sensitivity of the tool.

REFERENCES

1. Shah S, Vanclay F, Cooper B. Improving the sensitivity of the Barthel Index for stroke rehabilitation. Journal of Clinical Epidemiology. 1989;42(8):703–9.

2. de Morton NA, Keating JL, Davidson M. Rasch analysis of the Barthel Index in the assessment of hospitalized older patients after admission for an acute medical condition. Archives of Physical Medicine and Rehabilitation. 2008;89(4):641–7.

3. Leung SOC, Chan CCH, Shah S. Development of a Chinese version of the Modified Barthel Index - Validity and reliability. Clinical Rehabilitation. 2007;21(10):912–22.

4. Küçükdeveci A, Yavuzer G, Tennant A, Süldür N, Sonel B, Arasil T. Adaptation of the Modified Barthel Index for use in physical medicine and rehabilitation in Turkey. Scandinavian Journal of Rehabilitation Medicine. 2000;32(2):87–92.

5. Oveisgharan S, Shirani S, Ghorbani A, Soltanzade A, Baghaei A, Hosseini S, et al. Barthel Index in a Middle-East country: Translation, validity and reliability. Cerebrovascular Diseases. 2006;22(5-6):350–4.

6. Statistics South Africa. Statistical release: Mid-year population estimates [Internet]. 2015. Available from: http://www.statssa.gov.za/publications/P0302/P03022015.pdf

7. Freeme JD. The training and practice in neurological rehabilitation theories in the occupational therapy management of stroke patients in South Africa [dissertation]. Johannesburg: University of Witwatersrand; 2011.

8. Hsueh I, Lee M, Hsieh C. Psychometric characteristics of the Barthel Activities of Daily Living Index in stroke patients. Journal of the Formosan Medical Association. 2001;100(8):526–32.

9. Bennett S, Tooth L, McKenna K, Rodger S, Strong J, Ziviani J, et al. Perceptions of evidence-based practice: A survey of Australian occupational therapists. Australian Occupational Therapy Journal. 2003;50(1):13–22.

10. Noncommunicable diseases [Internet]. World Health Organization. 2015 [cited

2016 Feb 6]. Available from: http://www.who.int/mediacentre/factsheets/fs355/en/

11. Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. The Lancet. Elsevier Ltd; 2011;377(9778):1693–702.

12. Radomski VA, Trombly Latham CA. Occupational therapy for physical dysfunction. 6th Edition. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins; 2008.

13. Kniepmann K. Female family carers for survivors of stroke: Occupational loss and quality of life. British Journal of Occupational Therapy. 2012;75(5):208–16.

14. Murray CJL, Vos T, Lozano R, Naghavi M, Flaxman AD, Michaud C, et al. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: A systematic analysis for the Global Burden of Disease Study 2010. Lancet. Elsevier; 2012 Dec 15;380(9859):2197–223.

15. Connor MD, Walker R, Modi G, Warlow CP. Burden of stroke in black populations in sub-Saharan Africa. Lancet Neurology. 2007;6(3):269–78.

16. Lemogoum D, Degaute J-P, Bovet P. Stroke prevention, treatment, and rehabilitation in sub-Saharan Africa. American Journal of Preventive Medicine. 2005 Dec;29(5 Suppl 1):95–101.

17. Demaerschalk BM, Hwang H-M, Leung G. US cost burden of ischemic stroke: a systematic literature review. The American Journal of Managed Care. 2010;16(7):525–33.

18. De Wit L, Putman K, Lincoln N, Baert I, Berman P, Beyens H, et al. Stroke rehabilitation in Europe: What do physiotherapists and occupational therapists actually do? Stroke. 2006;37(6):1483–9.

19. American Occupational Therapy Association. Occupational therapy practice framework: Domain & process 3rd Edition. The American Journal of Occupational Therapy. 2014;68(Suppl. 1):S1–48.

20. World Health Organization. The International Classification of Functioning, Disability and Health. World Health Organization. 2001;18:237.

21. Quinn TJ, Langhorne P, Stott DJ. Barthel Index for stroke trials: Development, properties, and application. Stroke. 2011;42(4):1146–51.

22. Mahoney FI, Barthel DW. Functional evaluation: The Barthel Index. Maryland State Medical Journal. 1965;14(1):56–61.

23. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: A reliability study. International Disability Studies. 1988;10(2):61–3.

24. Hobart J, Thompson A. The five item Barthel Index. Journal of Neurology, Neurosurgery, and Psychiatry. 2001;71(2):225–30.

25. Ellul J, Watkins C, Barer D. Estimating total Barthel scores from just three items: The European Stroke Database “minimum dataset” for assessing functional status at discharge from hospital. Age and Ageing. 1998;27(2):115–22.

26. Schonle P. [The Early Rehabilitation Barthel Index--an early rehabilitation-oriented extension of the Barthel Index]. Die Rehabilitation. 1995;34(2):69–73.

27. Novak S, Johnson J, Greenwood R. Barthel revisited: Making guidelines work. Clinical Rehabilitation. 1996;10(2):128–34.

28. Barer D, Murphy J. Scaling the Barthel: A 10-point hierachiacal version of the Activities of Daily Living Index for use with stroke patients. Clinical Rehabilitation. 1993;7(4):271–7.

29. Van Hartingsveld F, Lucas C, Kwakkel G, Lindeboom R. Improved interpretation of stroke trial results using empirical Barthel Item weights. Stroke. 2006;37(1):162–6.

30. Galeoto G, Lauta A, Palumbo A, Sf C, Mollica R, Santilli V, et al. The Barthel Index: Italian translation, adaptation and validation. International Journal of Neurology and Neurotherapy. 2015;2(2):1–7.

31. Heuschmann P, Kolominsky-Rabas P, Nolte C, Hünermund G, Ruf H, Laumeier I, et al. [The reliability of the german version of the Barthel-Index and the development of a postal and telephone version for the application on stroke patients]. Fortschr Neurol Psychiatr. 2005;73(2):74–82.

32. Fricke J, Unsworth CA. Inter-rater reliability of the original and modified Barthel Index, and a comparison with the Functional Independence Measure. Australian Occupational Therapy Journal. 1996;43(1):22–9.

33. SouthAfrica.info. South Africa's population [Internet]. 2015. Available from: http://www.southafrica.info/about/people/population.htm#.VkZ26fkrLIU

34. Mesthrie R, editor. Language and social history: Studies in South African sociolinguistics. David Philip Publishers. Cape Town; 1995. xvii p.

35. Maleka MED. The development of an outcome measure to assess community reintegration after stroke for patients living in poor socioeconomic urban and rural areas of South Africa [dissertation]. Johannesburg: University of Witwatersrand; 2010.

36. Thomas E, Seager J, Viljoen E. Household Environment and Health in Port Elizabeth, South Africa [Internet]. Sweden; 1999. Available from: http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:Household+Environment+and+Health+in+Port+Elizabeth,+South+Africa#0

37. Abdool Karim SS, Zigubu-Page T, Arendse R. Bridging the gap. Durban; 1992.

38. Kale R. South Africa's health: Traditional healers in South Africa: A parallel health care system. BMJ. 1995;310(6988):1182–5.

39. Chiu L, Shyu W-C, Liu Y-H. Comparisons of the cost-effectiveness among hospital chronic care, nursing home placement, home nursing care and family care for severe stroke patients. Journal of Advanced Nursing. 2001;33(3):380–6.

40. Mamabolo M, Mudzi W, Stewart A, Olorunju S, Singh A. A study to determine post discharge functional improvements in patients with stroke. South African Journal of Occupational Therapy. 2009;39(1):15–8.

41. Statistics South Africa. General Household Survey. Pretoria; 2015.

42. Connor M, Tipping B, de Villiers L, Wainwright H, Candy S, Bryer A. Stroke in patients with human immunodeficiency virus infection. Journal of Neurology, Neurosurgery, and Psychiatry. 2007;78(12):1320–4.

43. Murdock C. A critical evaluation of the Barthel Index, part 1. British Journal of Occupational Therapy. 1992;55(3):109–11.

44. Foster D. The global etiquette guide to Africa and the Middle East: Everything you need to know for business and travel success. John Wiley & Sons I, editor. New York; 2002. 250 p.

45. Shaker R, Geenen JE. Management of dysphagia in stroke patients. Gastroenterology & Hepatology (N Y). 2011;7(5):308–32.

46. Martino R, Foley N, Bhogal S, Diamant N, Speechley M, Teasell R. Dysphagia after stroke: Incidence, diagnosis, and pulmonary complications. Stroke. 2005;36(12):2756–63.

47. Blackwell Z, Littlejohns P. A review of the management of dysphagia: A South African perspective. 2010;42(2):61–70.

48. de Villiers L, Badri M, Ferreira M, Bryer A. Stroke outcomes in a socio-economically disadvantaged urban community. South African Medical Journal. 2011;101(5):345–8.

49. Coetzee R. Funa - Food from Africa. Roots of traditional African food culture. Durban: Butterworth & Co. (SA) (PTY) LTD; 1982.

50. Sainsbury A, Seebass G, Bansal A, Young JB. Reliability of the Barthel Index when used with older people. Age and Ageing. 2005;34(3):228–32.

51. Duffy L, Gajree S, Langhorne P, Stott DJ, Quinn TJ. Reliability (inter-rater agreement) of the Barthel Index for assessment of stroke survivors: Systematic review and meta-analysis. Stroke. 2013;44(2):462–8.

52. Shah S, Cooper B, Maas F. The Barthel Index and ADL evaluation in stroke rehabilitation in Australia, Japan, the UK and the USA. Australian Occupational Therapy Journal. 1992;39(1):5–13.

53. Chan K, Fong K. Accidental falls among community dwelling people with chronic stroke in Hong Kong. Asian Journal of Gerontology & Geriatrics. 2013;8(2):61–7.

54. Maart S, Eide A, Jelsma J, Loeb M, Ka Toni M. Environmental barriers experienced by urban and rural disabled people in South Africa. Disability & Society. 2007;22(4):357–69.

55. Visagie S, Scheffler E, Schneider M. Policy implementation in wheelchair service delivery in a rural South African setting. African Journal of Disability. 2013;2(1):1–9.

56. Thompson HS, Ryan A. The impact of stroke consequences on spousal relationships from the perspective of the person with stroke. Journal of Clinical Nursing. 2009;18(12):1803–11.

57. World Health Organization. Global Health Observatory Data Repository [Internet]. Available from: http://apps.who.int/gho/data/node.main.620?lang=en

58. World Health Organization. Maternal, newborn, child and adolescent health [Internet]. Available from: http://www.who.int/maternal_child_adolescent/topics/maternal/adolescent_pregnancy/en/

59. Bastien S, Kajula LJ, Muhwezi WW. A review of studies of parent-child communication about sexuality and HIV/AIDS in sub-Saharan Africa. Reproductive Health. BioMed Central Ltd; 2011;8(1):25.

60. Wood K, Jewkes R. Blood blockages and scolding nurses: Barriers to adolescent contraceptive use in South Africa. Reproductive Health Matters. 2006 May;14(27):109–18.

61. Mellor RM, Greenfield SM, Dowswell G, Sheppard JP, Quinn T, McManus RJ. Health care professionals' views on discussing sexual wellbeing with patients who have had a stroke: A qualitative study. PLOS ONE. 2013;8(10):1–9.

62. Daniel K, Wolfe C, Busch M, Mckevitt C. What are the social consequences of stroke for working-aged adults?: A systematic review. Stroke. 2009;40(6):e431–40.

63. Duits A, van Oirschot N, van Oostenbrugge RJ, van Lankveld J. The relevance of sexual responsiveness to sexual function in male stroke patients. Journal of

Sexual Medicine. 2009;6(12):3320–6.

64. Carod J, Egido J, Gonzalez JL, Varela de Seijas E, Korpelainen JT. Poststroke sexual dysfunction and quality of life. Stroke. 1999;30(10):2238–48.

65. Kimura M, Murata Y, Shimoda K, Robinson RG. Sexual dysfunction following stroke. Comprehensive Psychiatry. 2001;42(3):217–22.

66. Jung JH, Kam SC, Choi SM, Jae SU, Lee SH, Hyun JS. Sexual dysfunction in male stroke patients: Correlation between brain lesions and sexual function. Urology. 2008;7(1):99–103.

67. Bray GP, DeFrank RS, Wolfe TL. Sexual functioning in stroke survivors. Archives of Physical Medicine and Rehabilitation. 1981;62(6):286–8.

68. Carod-Artal FJ, Egido JA. Quality of life after stroke: The importance of a good recovery. Cerebrovascular Diseases. 2009;27(Suppl. 1):204–14.

69. Green J, Forster A, Young J. A test-retest reliability study of the Barthel Index, the Rivermead Mobility Index, the Nottingham Extended Activities of Daily Living Scale and the Frenchay Activities Index in stroke patients. Disability and Rehabilitation. 2001;23(15):670–6.

70. Brink H. Fundamentals of Research Methodology for Health Care Professionals. 2nd Edition. Cape Town: Juta & Co.; 1996.

71. Granger C, Greer D, Liset E, Coulombe J, O'Brien E. Measurement of outcomes of care for stroke patients. Stroke. 1975;6(1):34–41.

72. Liu C, McNeil JE, Greenwood R. Rehabilitation outcomes after brain injury: Disability measures or goal achievement? Clinical Rehabilitation. 2004;18(4):398–404.

73. Wade DT, Hewer RL. Functional abilities after stroke: Measurement, natural history and prognosis. Journal of Neurology, Neurosurgery, and Psychiatry. 1987;50(2):177–82.

74. Hsueh I-P, Lin J-H, Jeng J-S, Hsieh C-L. Comparison of the psychometric characteristics of the Functional Independence Measure, 5 item Barthel Index,

and 10 item Barthel Index in patients with stroke. Journal of Neurology, Neurosurgery, and Psychiatry. 2002;73(2):188–90.

75. Haynes SN, Richard DCS, Kubany ES. Content validity in psychological assessment : A functional approach to concepts and methods introduction to content validity. Psychological Assessment. 1995;7(3):238–47.

76. McKenzie J, Wood M, Kotecki J, Clark J. Establishing content validity: Using qualitative and quantitative steps. American Journal of Health Behavior. 1999;23(4):311–8.

77. Mastaglia B, Toye C, Kristjanson LJ. Ensuring content validity in instrument development: Challenges and innovative approaches. Contemporary Nurse. 2003;14(3):281–91.

78. Newman I, Lim J, Pineda F. Content validity using mixed methods approach : Its application and development through the use of a Table of Specifications methodology. Journal of Mixed Methods Research. 2013;7(3):243–60.

79. van Breda A. Steps to analysing multiple-group NGT data. The Social Work Practitioner-Researcher. 2005;17(1):1–14.

80. Harvey N, Holmes CA. Nominal group technique: An effective method for obtaining group consensus. International Journal of Nursing Practice. 2012;18:188–94.

81. Deslandes SF, Mendes CHF, Pires TDO, Campos DDS. Use of the nominal group technique and the Delphi method to draw up evaluation indicators for strategies to deal with violence against children and adolescents in Brazil. Revista Brasileira de Saúde Materno Infantil. 2010;10(Suppl.1):s29–37.

82. Van De Camp K, Vernooij-Dassen M, Grol R, Bottema B. Professionalism in general practice: Development of an instrument to assess professional behaviour in general practitioner trainees. Medical Education. 2006;40(1):43–50.

83. Gibson D, Velde B, Hoff T, Kvashay D, Manross PL, Moreau V. Clinical Reasoning of a Novice versus an Experienced Occupational Therapist: A

Qualitative Study. Occupational Therapy In Health Care. 2000;12(4):15–31.

84. McMillan S, Kelly F, Sav A, Kendall E, King M, Whitty J, et al. Using the nominal group technique: How to analyse across multiple groups. Health Services and Outcomes Research Methodology. 2014;14(3):92–108.

85. University of Glasgow. The Barthel Index of Activities of Daily Living [Internet]. 2015. Available from: https://secure.trainingcampus.net/UAS/Modules/TREES/windex.aspx

86. Shah S, Cooper B. Commentary on “A critical evaluation of the Barthel Index.” British Journal of Occupational Therapy. 1993;56(2):70–2.

APPENDIX A

MODIFIED BARTHEL INDEX (SHAH VERSION)		
Index/Item	**Score**	**Description of score**
CHAIR/BED TRANSFERS	**0**	Unable to participate in a transfer. Two attendants are required to transfer the patient with or without a mechanical device.
	3	Able to participate but maximum assistance of one other person is require in all aspects of the transfer.
	8	The transfer requires the assistance of one other person. Assistance may be required in any aspect of the transfer.
	12	The presence of another person is required either as a confidence measure, or to provide supervision for safety.
	15	The patient can safely approach the bed walking or in a wheelchair, lock brakes, lift footrests, or position walking aid, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, transfer back into it safely. The patient must be independent in all phases of this activity.
AMBULATION (Walking)	**0**	Dependent in ambulation.
	3	Constant presence of one or more assistant is required during ambulation.
	8	Assistance is required with reaching aids and/or their manipulation. One person is required to offer assistance.
	12	The patient is independent in ambulation but unable to walk 50 metres/yards without help, or supervision is needed for confidence or safety in hazardous situations.
	15	The patient must be able to wear braces if required, lock and unlock these braces assume standing position, sit down, and place the necessary aids into position for use. The patient must be able to crutches, canes, or a walkarette, and walk 50 metres/yards without help or supervision.
WHEELCHAIR MANAGEMENT * Only use this item if the patient is rated "0" for ambulation, and then only if the patient has been trained in w/c management.	**0**	Dependent in wheelchair ambulation.
	1	Patient can propel self short distances on flat surface, but assistance is required for all other steps of wheelchair management.
	3	Presence of one person is necessary and constant assistance is required to manipulate chair to table, bed, etc.
	4	The patient can propel self for a reasonable duration over regularly encountered terrain. Minimal assistance may still be required in "tight corners"
	5	To propel wheelchair independently, the patient must be able to go around corners, turn around, manoeuvre the chair to a table, bed, toilet, etc. The patient must be able to push a chair at least 50 metres/yards
STAIRS	**0**	The patient is unable to climb stairs.
	2	Assistance is required in all aspects of stairclimbing, including assistance with walking aids.
	5	The patient is able to ascend/descend but is unable to carry walking aids and needs supervision and assistance.
	8	Generally no assistance is required. At times supervision is required for safety due to morning stiffness, shortness of breath, etc.
	10	The patient is able to go up and down a flight of stairs safely without help or supervision. The patient is able to use hand rails, cane or crutches when needed and is able to carry these devices as he/she ascends or descends.

ON AND OFF THE TOILET	**0**	Fully dependent in toileting.
	2	Assistance required in all aspects of toileting.
	5	Assistance may be required with management of clothing, transferring, or washing hands.
	8	Supervision may be required for safety with normal toilet. A commode may be used at night but assistance is required for emptying and cleaning.
	10	The patient is able to get on/off the toilet, fasten clothing and use toilet paper without help. If necessary, the patient may use a bed pan or commode or urinal at night, but must be able to empty it, and clean it.
BOWELS	**0**	The patient is bowel incontinent.
	2	The patient needs help to assume appropriate position, and with bowel movement facilitatory techniques.
	5	The patient can assume appropriate position, but cannot use facilitatory techniques or clean self without assistance and has frequent accidents. Assistance is required with incontinence aids such as pad, etc.
	8	The patient may require supervision with the use of suppository or enema and has occasional accidents.
	10	The patient can control bowels and has no accidents, can use suppository, or take an enema when necessary.
BLADDER	**0**	The patient is dependent in bladder management, is incontinent, or has indwelling catheter.
	2	The patient is incontinent but is able to assist with the application of an internal or external device.
	5	The patient is generally dry by day, but not at night and needs some assistance with the devices.
	8	The patient is generally dry by day and night, but may have an occasional accident or need minimal assistance with internal or external devices.
	10	The patient is able to control bladder day and night, and/or is independent with internal or external devices.
BATHING SELF	**0**	Total dependence in bathing self.
	1	Assistance is required in all aspects of bathing.
	3	Assistance is required with either transfer to shower/bath or with washing or drying; including inability to complete a task because of condition or disease, etc.
	4	Supervision is required for safety in adjusting the water temperature, or in the transfer.
	5	The patient may use a bathtub, a shower, or take a complete sponge bath. The patient must be able to do all the steps of whichever method is employed without another person being present.
DRESSING	**0**	The patient is dependent in all aspects of dressing and is unable to participate in the activity.
	2	The patient is able to participate to some degree, but is dependent in all aspects of dressing.
	5	Assistance is needed in putting on, and/or removing any clothing.
	8	Only minimal assistance is required with fastening clothing such as buttons, zips, bra, shoes, etc.
	10	The patient is able to put on, remove, corset, braces, as prescribed.
PERSONAL HYGIENE	**0**	The patient is unable to attend to personal hygiene and is dependent in all aspects.
	1	Assistance is required in all steps of personal hygiene, but patient able to make some contribution.
	3	Some assistance is required in one or more steps of personal hygiene.
	4	Patient is able to conduct his/her own personal hygiene but requires minimal assistance before and/or after the operation.

(Grooming)	**5**	The patient can wash his/her hands and face, comb hair, clean teeth and shave. A male patient may use any kind of razor but must insert the blade, or plug in the razor without help, as well as retrieve it from the drawer or cabinet. A female patient must apply her own make-up, if used, but need not braid or style her hair.
FEEDING	**0**	Dependent in all aspects and needs to be fed.
	2	Can manipulate an eating device, usually a spoon, but someone must provide active assistance during the meal.
	5	Able to feed self with supervision. Assistance is required with associated tasks such as putting milk/sugar into tea, salt, pepper, spreading butter, turning a plate or other “set up” activities.
	8	Independence in feeding with prepared tray, except may need meat cut, milk carton opened or jar lid etc. The presence of another person is not required.
	10	The patient can feed self from a tray or table when someone puts the food within reach. The patient must put on an assistive device if needed, cut food, and if desired use salt and pepper, spread butter, etc.

APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE:

OCCUPATIONAL THERAPISTS & PHYSIOTHERAPISTS

DEMOGRAPHIC DETAILS:

1. Undergraduate qualification: _____
2. University of undergraduate qualification: _____
3. Year of undergraduate qualification (final year): _____
4. Postgraduate degree/courses attended which are relevant to neurological rehabilitation:

   _____

   _____
5. Years of experience as a therapist (incl. community service): _____
6. Years of clinical experience in neurological rehabilitation: _____
7. Please indicate the type of setting you work in:

   - Government
   - Private hospital
   - Private practice
   - Primary health care clinic
   - Academic facility
   - Neurorehabilitation centre
   - Other

   If other, please specify: _____

8. Did you receive training on using the Barthel Index (any version) on an undergraduate level?

   Yes No Not sure
9. Have you administered the Barthel Index (any version) on a patient?

   Yes No Not sure

ELSEVIER LICENSE TERMS AND CONDITIONS

APPENDIX C

Nov 13, 2015

This is an Agreement between Fiona Millan ("You") and Elsevier ("Elsevier"). It consists of your order details, the terms and conditions provided by Elsevier, and the payment terms and conditions.

All payments must be made in full to CCC. For payment instructions, please see information listed at the bottom of this form.

Supplier	Elsevier Limited The Boulevard,Langford Lane Kidlington,Oxford,OX5 1GB,UK
Registered Company Number	1982084
Customer name	Fiona Millan
Customer address	41 HF Verwoerd Street Mokopane, Limpopop 0601
License number	3337210116859
License date	Feb 27, 2014
Licensed content publisher	Elsevier
Licensed content publication	Journal of Clinical Epidemiology
Licensed content title	Improving the sensitivity of the Barthel Index for stroke rehabilitation
Licensed content author	Surya Shah,Frank Vanclay,Betty Cooper
Licensed content date	1989
Licensed content volume number	42
Licensed content issue number	8
Number of pages	7
Start Page	703
End Page	709
Type of Use	reuse in a thesis/dissertation
Portion	full article
Format	both print and electronic
Are you the author of this Elsevier article?	No
Will you be translating?	No
Title of your thesis/dissertation	The Content Validity of the Modified Barthel Index in Stroke Patients in South Africa
Expected completion date	Feb 2015
Estimated size (number of pages)	175
Elsevier VAT number	GB 494 6272 12
Price	0.00 USD
VAT/Local Sales Tax	0.00 USD / 0.00 GBP
Total	**0.00 USD**
Terms and Conditions	

APPENDIX D

R14/49 Ms Fiona Millian

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130810

NAME: (Principal Investigator)	Ms Fiona Millian
DEPARTMENT:	Occupational Therapy Johannesburg, South Africa
PROJECT TITLE:	Content Validity of the Modified Barthel Index in Stroke Patients in South Africa
DATE CONSIDERED:	30/08/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Juliana Freeme
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	30/10/2013

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 E

INFORMATION LETTER TO PARTICIPANTS

Good day,

I am Fiona Breytenbach and I am completing my MSc Occupational Therapy (Neurosciences) degree through the University of the Witwatersrand. I am doing my research on establishing **The Content Validity of the Modified Barthel Index in Stroke Patients in South Africa**.

Introduction

This sheet will provide you with the information and invitation to be part of this study. You are welcome to accept or decline to participate in this study. I encourage you to take some time before deciding and you are welcome to talk to anyone about this invitation. If you do not understand any of the words or concepts or if you have any questions at any point throughout the research, you may contact me at any time and I will ensure I address your questions.

What is the purpose of the study?

It is a great concern that the most commonly practiced and trained method for neurological assessments, in South Africa, is based on our general observations. The results of these observations may vary greatly and are therefore unreliable as they are subjective interpretations. Our use of general observations may be because there are very few outcome measures that have been tested to be reliable and valid for the South African population. It is therefore my aim to test the content validity of the Modified Barthel Index (MBI), an outcome measure which assesses one's functioning in activities of daily living, for the South African stroke population.

Research Procedure

A group discussion of 4 – 9 participants will be arranged at a venue that is suitable and convenient to all participants during November 2014 - August 2015. You will be asked to complete a self-administered demographic questionnaire prior to the discussion group which should take approximately 10 minutes. Also, each participant will be given sufficient time to read through each item of the MBI before the discussion. Tea and snacks will be provided. The discussion will be approximately 90 minutes in duration. The primary researcher will moderate the discussion. Group participants are expected to actively participate in responding to questions posed by the moderator, discussing/elaborating on ideas and ranking ideas in order to reach a group consensus. Please note that the entire discussion will be audio-recorded and later transcribed for data analysis purposes only.

Your participation in this study is entirely voluntary. If you choose not to participate there will be no negative consequences. You may change your decision at any time and can stop participating even if you agreed earlier. You may request that the information you provided in the discussion not be used in the study.

Confidentiality

I will not be sharing any personal or professional information about you to anyone outside the research team and all data collected from this research will be kept confidential. Audiotapes will be stored for 6 years in a locked secure location according to HPCSA regulations. In all documents and data sheets, you will be assigned a random number as an identification tag in order to maintain your anonymity. Only a third party person will have access to your personal information which will be a password protected document. However, taking part in a group

discussion is a research risk because once something is said in the group, I cannot stop participants sharing this information outside the group when it should be kept confidential. That said, I encourage each participant in the group to keep confidential what is shared in the group.

Contact Details

For further information/reporting of study related events please contact the Wits Occupational Therapy Department on 011 717 3701. Please contact the Chairman of the ethics committee, Prof P Cleaton-Jones at anisa.keshav@wits.ac.za or at 011 717 1234 if you have any complaints or problems.

Thank you for your consideration.



Fiona Breytenbach
Primary Researcher
Tel. 076 048 5478
Fax. 086 760 8091
E-mail: fionamillan@gmail.com

APPENDIX F

INFORMED CONSENT FROM PARTICIPANTS TO PARTICIPATE IN THE STUDY

I acknowledge that I have been invited to participate in a study researching **The Content Validity of the Modified Barthel Index in Stroke Patients in South Africa**. I have read the foregoing information. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction.

I consent to the researcher using the results found in the study (excluding my name)

I am aware that my participation in the study is voluntary and that I may withdraw at any stage.

Name and surname: _____

Signature of participant _____



Fiona Breytenbach
Primary Researcher
Tel. 076 048 5478
Fax. 086 760 8091
E-mail: fionamillan@gmail.com

APPENDIX G

INFORMED CONSENT FROM PARTICIPANTS FOR GROUP TO BE AUDIO RECORDED

I acknowledge that I have been invited to participate in a study researching **The Content Validity of the Modified Barthel Index in Stroke Patients in South Africa**. I have read the foregoing information.

I understand that the group discussion will be **audio-recorded** and saved for data analysis purposes and that the transcript will be stored safely by the primary researcher and destroyed once the research is complete.

I consent to the researcher:

- Audio taping the discussion group

Name and surname: _____

Signature of participant _____



Fiona Breytenbach
Primary Researcher
Tel. 076 048 5478
Fax. 086 760 8091
E-mail: fionamillan@gmail.com

APPENDIX H

Results of NGT Discussion Groups

Question 1

Question 1: List of statements

Table 7.1. List of statements generated by four nominal group technique discussion groups for Question 1, sorted according to theme

Group	Theme	Statement	Scores	Sum	Average	Top 5
2	1A	OT & OTTs & OTAs and PT primarily	4+3+2+2+1	12	2.40	x
2	1A	If only one: OTs ideally	3+2+1	6	1.20	x
3	1A	Any qualified OT/PT+ not assistants. Ots and PTs understand the limitations and understand the language used.	4+3	7	2.33	x
4	1B	OTs and OTAs/OTTs+ PTs and PTAs+ nurses (trained/stroke unit)	5+5+5	15	5.00	x
1	1B	Rehab team (excluding Doctors and inlcuding nurses)	5+4+4+3	16	4.00	x
1	1B	Physios+ OTs+ Nurses	3+2+2+2	9	2.25	x
2	1B	OT+ PT+ SLT+ Nursing staff collectively complete diff sections because allows discussion to get clear picture	5+5+5+5+3	23	4.60	x
2	1B	OTs and physios and nurses should be able to complete individually	3+3	6	1.20	x
1	1C	MDT should complete as a group	5+5+4+3	17	4.25	x
2	1C	MDT ideally (Dr+ nurse+ physio+ speech)	5+4+4+4+4	21	4.20	x
1	1D	PT+ OT+ Nurse+ Dr+ caregiver+ and patient individually complete	5+4+3+2	14	3.50	x

3	1D	Anybody working with neuro pts (therapists/assistants/nurses/ caregivers possibly)	5+5+2	12	4.00	x
3	1D	Items are specific enough for everyone to used. Few words may be difficult to understand. Subjective nature of test affects everyone	4+4+2	10	3.33	x
3	1D	Would be beneficial if caregivers/patients could use (language would need to be changed – the patients we deal with will not understand the sentences in the MBI)	3	3	1.00	x
2	1E	Nurses individually	2+2	4	0.80	
2	1E	Nurses and Doctors should have general understanding	1+1+1	3	0.60	

Question 1: Final Rank

Table 7.2. Rankings of Question 1 themes, sorted according to final rank

Theme	No. of Top 5	Ranked importance	Frequency of statements	Ranked frequency of statements	Average	Ranked averages	Final Rank
1B	5	5.00	5	5.00	3.41	4.00	**14**
1D	4	4.00	4	4.00	2.96	3.00	**11**
1C	2	2.00	2	1.50	4.23	5.00	**9**
1A	3	3.00	3	3.00	1.98	2.00	**8**
1E	0	1.00	2	1.50	0.70	1.00	**4**

Question 2

Question 2: List of statements

Table 7.3. List of statements generated by four nominal group technique discussion groups for Question 2, sorted according to theme

Group	Theme	Statement	Scores	Sum	Average	Top 5
1	2A	The most common African language (Zulu)	4+4+4+4	16	4.00	x
3	2A	Zulu and sotho most popular African language in Johannesburg	3+3+3	9	3.00	x
2	2A	Maybe Zulu because majority of patients are Zulu	3+1+1	5	1.00	
1	2B	English because most HCPs are trained in English	5+3+3+2	13	3.25	x
1	2B	If completed in a group+ can overcome language barrier	3+3+2	8	2.00	x
2	2B	English because administered by therapists who can understand English and does not need patient's understanding (observation)	4+4+3	11	2.20	x
2	2B	English because hospital policy (all comm. In English)	4+3+2+1	10	2.00	x
4	2B	English because HCP is using observation+ not asking	5+4+4	13	4.33	x
4	2B	English because HCPs are trained in English in SA – keeps it standard	5+4+3	12	4.00	x
1	2C	Simple English so that 2nd language persons can complete+ although would need to be revalidated	5+2	7	1.75	x
1	2C	Use English+ unless they can't read and write	5+1	6	1.50	x
2	2C	English because everyone has a general understanding	5+5+5+3+2	20	4.00	x

3	2C	English version is most needed because it is the medium of instruction at schools and people tend to prefer the English version+ patients and caregivers tend to understand spoken English	5+4+4	13	4.33	x
2	2D	Shouldn't be able to be translated+ however may be difficult for administrator – would become more self-administering if translated – rather use translator to assist	4+3+2+1+1	11	2.20	x
4	2D	Shouldn't be translated as all HCPs should be able to understand and words get lost in translation	5+3+3	11	3.67	x
1	2E	If unable to understand English+ then they need to have it translated	5+1	6	1.50	x
2	2E	Should be able to be available in other languages but shouldn't change content and therefore can be used more widely	5+5+4+2+2	18	3.60	x
3	2E	Language depends on area – varies throughout south Africa (all 11 languages)	5+5+4	14	4.67	x

Question 2: Final Rank

Table 7.4. Rankings of Question 2 themes, sorted according to final rank

Theme	No. of Top 5	Ranked importance	Frequency of statements	Ranked frequency of statements	Average	Ranked averages	Final Rank
2B	6	5.00	6	5.00	2.96	4	**14**
2E	3	3.00	3	2.50	3.26	5	**11**
2C	4	4.00	4	4.00	2.90	2	**10**
2D	2	1.50	2	1.00	2.93	3	**6**
2A	2	1.50	3	2.50	2.67	1	**5**

Question 3

Question 3: List of statements

Table 7.5. List of statements generated by four nominal group technique discussion groups for Question 3, sorted according to theme

Group	Theme	Statement	Scores	Sum	Average	Top 5
1	3A	Words should be quantified as some words are vague (appropriate, some, some degree, minimal)	4+3+3	10	2.50	x
2	3A	Should be more clear (vague) – specify/quantify how much assistance or how often (e.g. using percentages, words like min/mod/max may be vague)	5+5+5+5+3	23	4.60	x

4	3A	Clarify “maximum”+ “moderate’ and “minimum” – quantify. Use “1 person” or “2 person” etc. Be more consistent throughout items. Percentages also could be used to quantify these words – a key/description should of percentages should be provided on document.	5+5+5	15	5.00	x
4	3A	MBI doesn’t make a distinction between (or use of) verbal and physical assistance	4+3+2	9	3.00	x
1	3B	Could include explanations of key words (assistance+ supervision+ dependence+ wheelchair ambulation)	4+4+4+2	14	3.50	x
1	3B	Words can be changed to more simple words+ without changing meaning+ although would have to be revalidated (e.g. ambulation can be walking+ or ascend and descend can be up/down etc..)	5+5+3	13	3.25	x
1	3B	Should be phrased in simpler+ more descriptive terms (Written for professionals (long words) – designed for health professionals)	5+5+2	12	3.00	x
1	3B	Some health care professionals do not have English as 1st language	1	1	0.25	
2	3B	If all MDT involved+ use laymans terms (e.g. “attendance” not clear) as terms may not be familiar	5+4+4+4+2	19	3.80	x
2	3B	Should be clear and simple overall – some items are difficult to understand (e.g. using ‘people’ instead of ‘attendants’)	2.2	4	0.80	

3	3B	Substitute words that are more common: Propel – push+ Terrain – ground+ Attendant – rather use helper+ Assistance – rather use help+ Ascend – going up+ descend – going down+ Kerb – raised path near side of road or pavement+ or define in definition sheet+ 'Ambulation' rather use 'moving' or 'walking' or 'using a wheelchair'+ Walkerette – rather use walking frame or needs to be investigated+ Incontinence – rather use description (not able to control bowel and has accidents)	5+5+5	15	5.00	x
3	3B	Definition sheet with MBI (appendix) to refer to+ with words that need to be described. Some words need to be made more simple or defined in definition sheet (e.g. bowel and bladder)	4+4+3	11	3.67	x
4	3B	Use a simpler terms e.g. "up" for ascend+ "short distance"	4+2+1	7	2.33	x
1	3B	Some words should be more contextually relevant (e.g. types of walking aids we use)	3+2+2+1	8	2.00	x
2	3B	Some terms not familiar (e.g. walkerette) -will make a difference if different materials used	3+2+1	6	1.20	x
2	3B	Have more range with regard to what kind of clothing used in dressing	1+1+1	3	0.60	
3	3C	Some words are not a terminology problem+ but an English problem+ If the words are translated into their language they might understand it better	4+3+3	10	3.33	x
4	3D	Overall+ the MBI needs to be more consistent	4+3+3	10	3.33	x
1	3E	Some words may be hard to translate (not exact words+ or misunderstanding)	1	1	0.25	

2	3F	Phrasing should be more descriptive if patient needs assistance to set-up (e.g. must something be brought?) – how must it be set-up exactly	4+3+3+3+1	14	2.80	x
2	3F	Be more specific wrt upper body/ lower body dressing	4.2	6	1.20	x
4	3F	If there is a profession-specific item – rather break up into steps so that the terminology is understood (by the specific HCP)	2+1+1	4	1.33	x

Question 3: Final Rank

Table 7.6. Rankings of Question 3 themes, sorted according to final rank

Theme	No. of Top 5	Ranked importance	No. of statements	Ranked frequency of statements	Average	Ranked averages	Final Rank
3A	5	6.00	7	5.50	2.63	7.00	**19**
3B	6	7.00	8	7.00	1.94	5.00	**19**
3E	4	5.00	7	5.50	1.23	2.00	**13**
3D	3	4.00	5	4.00	1.76	4.00	**12**
3F	1	2.00	1	1.00	2.33	6.00	**9**
3C	1	2.00	2	2.50	1.27	3.00	**8**
3G	1	2.00	2	2.50	0.83	1.00	**6**

Question 4

Question 4: List of statements

Table 7.7. List of statements generated by four nominal group technique discussion groups for Question 4, sorted according to theme

Group	Theme	Statement	Scores	Sum	Average	Top 5
1	4A	Sexual activity relevant but may be difficult to gain information	4+2	6	1.50	x
3	4A	Include sexual activity – often left out but vital to patient and important – may not be applicable to some patients	5+4	9	3.00	x
4	4A	Include sexual activity if it is used as comprehensive assessment (rehab unit)	2+2+1	5	1.67	x
1	4B	Eating not in MBI – should be included – should be distinguished from feeding	4+3+3	10	2.50	x
2	4C	Should split UL and LL in dressing item because different difficulty levels	4+2	6	1.20	
4	4C	Distinguish UL & LL dressing as in FIM/FAM because patients function differently in these	3+3+1	7	2.33	x
2	4D	Personal device care should be included in MBI	4+3+2+2+2	13	2.60	x
3	4D	Personal device care should be included – look after wheelchair and assistive devices (e.g. splints)	2	2	0.67	
4	4D	Include personal device care if it is used as comprehensive assessment (rehab unit)	2+2+1	5	1.67	x
1	4E	In MBI+ bathing should be called ‘washing yourself	5	5	1.25	x

2	4E	Bathing item biased to urban – terminology – western terminology - biased	5	5	1.00	
3	4E	Bathing – should include fetch water and empty bathtub	5	5	1.67	x
3	4F	Personal hygiene – should include retrieving items (women)	4	4	1.33	x
3	4G	Feeding – should include retrieving food to score full independence	3	3	1.00	
2	4H	Include in-bed mobility as an item because it tells us if patient has trunk control problems/balance	4+3+3	10	2.00	x
3	4H	Combine transfers with sub-heading (chair-bed+ toilet+ car/taxi) – transfers require similar movements	5+4	9	3.00	x
3	4H	Use functional mobility with sub-headings (walking+ wheelchair and stair climbing)	3+2	5	1.67	x
3	4H	Include running under functional mobility	1	1	0.33	
4	4H	Include bed mobility as an item	5+5+5	15	5.00	x
1	4I	In MBI toilet transfer is not correct (includes toilet hygiene)	4	4	1.00	x
2	4I	Toilet hygiene does not include dressing and cleaning body– important	1	1	0.20	
3	4J	Bowel and bladder control – should include management	2+1	3	1.00	
2	4K	Barthel can be used widely since it is free and accessible and should therefore be more specific	5+5+5+2	17	3.40	x
2	4K	Generalizing in MBI can be misinterpreted	4+4+1	9	1.80	x

4	4K	Items should be re-ordered from most to least difficult	4+4+4	12	4.00	x
1	4K	Participation in hospital does not reflect their participation at home	5+5	10	2.50	x
2	4K	If we don't add items it might not come up in Rx programme if used as sole ADL assessment	3+3+1+1	8	1.60	x
1	4L	Bowel and bladder separate is good – as one may differentiate from other and treated/recovers differently [no changes to be made]	3+1	4	1.00	x
1	4L	Stair climbing not particularly relevant to SA – but due to change – should be retained in MBI [no changes to be made]	2	2	0.50	
1	4L	Functional mobility better described in MBI – separate items [no changes to be made]	1	1	0.25	
2	4L	I wouldn't add anything more because MBI should be quick and easy (rather use another tool) – would be too long and if used by other HCPs – we may lose them in jargon [no changes to be made]	5+1	6	1.20	
4	4L	Eating is profession-specific (STs) and therefore shouldn't be on MBI [no changes to be made]	3	3	1.00	
4	4L	Nice that mobility is broken up into sections (e.g. walking+ W/C mobility) [no changes to be made]	2	2	0.67	
4	4L	Nothing needs to be excluded [no changes to be made]	1	1	0.33	

Question 4: Final Rank

Table 7.8. Rankings of Question 4 themes, sorted according to final rank

Theme	No. of Top 5	Ranked importance	Frequency of statements	Ranked frequency of statements	Average	Ranked averages	Final Rank
4K	5	12.00	5.00	10.50	2.66	12.00	**35**
4H	4	11.00	5.00	10.50	2.40	10.00	**32**
4A	3	10.00	3.00	8.00	2.06	9.00	**27**
4D	2	8.50	3.00	8.00	1.64	7.00	**24**
4E	2	8.50	3.00	8.00	1.31	5.00	**22**
4B	1	5.00	1.00	2.50	2.50	11.00	**19**
4C	1	5.00	2.00	5.50	1.77	8.00	**19**
4L	1	5.00	7.00	12.00	0.71	2.00	**19**
4F	1	5.00	1.00	2.50	1.33	6.00	**14**
4I	1	5.00	2.00	5.50	0.60	1.00	**12**
4G	0	1.50	1.00	2.50	1.00	3.50	**8**
4J	0	1.50	1.00	2.50	1.00	3.50	**8**

Question 5

Question 5: List of statements

Table 7.9. List of statements generated by four nominal group technique discussion groups for Question 5, sorted according to theme

Group	Theme	Statement	Scores	Sum	Average	Top 5
1	5A	Environment causes limitation to function (space. fixtures. distance. accessible terrain) – MBI assumes this	5+5+5	15	3.75	x
1	5A	Toileting transfer is more complicated (outside)	4+4	8	2.00	x
1	5A	Ambulation and W/C use difficult due to rough terrain and constrained spaces	3	3	0.75	
2	5A	Environments are less limiting in western countries (accessibility. home adaptations) – not case in SA	4+4	8	1.60	x
2	5A	Wheelchair ambulation: we don't have access to even terrain – consider rough terrain – difficult and wheelchair breaks	5	5	1.00	
3	5A	Most problems are related to socio-economic status and environmental barriers (terrain. accessibility of buildings and transport) – negatively affects ADLs on a large scale	5+5+5	15	5.00	x
4	5A	Location of ADLs differ (bathroom vs. room). Terrain outside house (rough terrain) and space and no lifts – these affect mobility	5+5+3	13	4.33	x
1	5B	Environment causes limitation to function (running water. electricity) – MBI assumes this	5+5+5	15	3.75	x
1	5B	Water is collected from communal taps with container	4	4	1.00	x
1	5B	Bathing doesn't include collecting water	2	2	0.50	

2	5B	Environments are less limiting in western countries (running water. electricity) – not case in SA	3+3+2	8	1.60	x
3	5B	Fetch water in SA compared to those who have a tap	4+2	6	2.00	x
3	5B	Electricity a limiting factor. fetch wood to prepare food	1	1	0.33	
4	5B	Availability of resources (electricity. water) e.g. often have to fetch water for bathing and toilet is often outside and often a pit toilet	5+4+4	13	4.33	x
4	5B	Transfers in SA are different (taxi and floor for sleeping)	3+3	6	2.00	x
2	5C	Due to lack of education or knowledge – believe in witchcraft – will seek help from traditional healers	5+1	6	1.20	
4	5C	Lack of knowledge about assistive devices(e.g. splints) affects their use of it. resulting in impaired functioning and poor attitude toward assistive devices affects their use of it resulting in impaired functioning	2+2	4	1.33	x
2	5D	Far more access to resources available in western countries (would score higher in MBI) – assistive devices are free in some countries	4+4	8	1.60	x
2	5D	Financial constraints in SA	3+3	6	1.20	
3	5D	Affordability and accessibility of assistive devices (e.g. ideal assistive devices not available)– limiting	4+4+2	10	3.33	x
3	5D	More pressure in hospitals (staff shortages and bed occupancy) – less time in rehab – negatively affects ADLs	3+3	6	2.00	x
4	5D	Lack of assistive devices in SA often – affects functioning	1+1	2	0.67	
1	5E	Feeding often hands are used/are appropriate	3+3+1	7	1.75	x

2	5E	Bathing differs to culture/class (e.g. basin. bath) – basin bath is norm in SA	5+2	7	1.40	x
2	5E	Should look at how patient was doing ADL premorbidly	4+2+1	7	1.40	x
2	5E	Different etiquette in most ADLs	5+1	6	1.20	
2	5E	Feeding is normal to eat with hands instead of fork and knife in some groups - culture	4	4	0.80	
2	5E	Majority female patients in government hospital don't wear pants - wear skirts	2	2	0.40	
3	5E	Diversity of cultures in health setting (clothes. feeding. toileting differences)	3+2	5	1.67	x
4	5F	In our culture. families are "enablers" and tend to help patients more. especially male patients have a role to be taken care of. female patients being cared for by female caregivers are "overcared"	4+2+1	7	2.33	x
1	5G	Patient may score well in hospital in MBI – different to home	2+2	4	1.00	x
3	5G	SA patients were less functional on discharge compared to admission to western countries – South African patients are less functional	1+1	2	0.67	

Question 5: Final Rank

Table 7.10. Rankings of Question 5 themes, sorted according to final rank

Theme	No. of Top 5	Ranked importance	Frequency of statements	Ranked frequency of statements	Average	Ranked averages	Final Rank
5A	5	6	7	5.50	2.63	7	**19**

5B	6	7	8	7.00	1.94	5	**19**
5C	1	2	2	2.50	1.27	3	**8**
5D	3	4	5	4.00	1.76	4	**12**
5E	4	5	7	5.50	1.23	2	**13**
5F	1	2	1	1.00	2.33	6	**9**
5G	1	2	2	2.50	0.83	1	**6**