UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences
School of Health Care Sciences
Department of Occupational Therapy

DEVELOPMENT OF AN OUTCOME MEASURE BASED ON MOTIVATION AND ACTION FOR OCCUPATIONAL THERAPISTS IN NEUROLOGICAL REHABILITATION

Author: Samantha Lee

Submitted in accordance with the requirements for the degree

Masters in Occupational Therapy

Supervisor: Mrs Jodie de Bruyn

Co-supervisor: Mrs Veronica Ramodike

2018

DECLARATION

Student number: 11157268

I, Samantha Anne Lee, hereby declare that this study entitled **Development of an outcome measure based on motivation and action for occupational therapists in neurological rehabilitation** is my own work. It is being submitted for degree purposes, for the degree Masters in Occupational Therapy from the University of Pretoria. It has not been submitted before for any degree or examination at this or any other university.

_____

Samantha Anne Lee

On this 10th day of December 2018

DECLARATION OF ORIGINALITY

UNIVERSITY OF PRETORIA

The Department of Occupational Therapy places great emphasis upon integrity and ethical conduct in the preparation of all written work submitted for academic evaluation.

While academic staff teach you about referencing techniques and how to avoid plagiarism, you too have a responsibility in this regard. If you are at any stage uncertain as to what is required, you should speak to your lecturer before any written work is submitted.

You are guilty of plagiarism if you copy something from another author's work (e.g. a book, an article or a website) without acknowledging the source and pass it off as your own. In effect, you are stealing something that belongs to someone else. This is not only the case when you copy work word-for-word (verbatim), but also when you submit someone else's work in a slightly altered form (paraphrase) or use a line of argument without acknowledging it. You are not allowed to use work previously produced by another student. You are also not allowed to let anybody copy your work with the intention of passing if off as his/her work.

Students who commit plagiarism will not be given any credit for plagiarised work. The matter may also be referred to the Disciplinary Committee (Students) for a ruling. Plagiarism is regarded as a serious contravention of the University's rules and can lead to expulsion from the University.

The declaration which follows must accompany all written work submitted while you are a student of the Department of Occupational Therapy. No written work will be accepted unless the declaration has been completed and attached.

Full names of student: Samantha Anne Lee

Student number: 11157268

Topic of work: Development of an Outcome Measure Based on Motivation and Action for Occupational Therapists in Neurological Rehabilitation

Declaration

1. I understand what plagiarism is and am aware of the University's policy in this regard.
2. I declare that this thesis is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.
3. I have not used work previously produced by another student or any other person to hand in as my own.
4. I have not allowed and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

SIGNATURE: Samantha Anne Lee

PRESENTATIONS ARISING FROM THE STUDY

1. Life Groenkloof Hospital, Rehabworx. Protocol for: The Development of an Outcome Measure based on Motivation and Action for Occupational Therapists working in Neurological Rehabilitation. 2017
2. Life Groenkloof Hospital, Rehabworx. Results of: The Development of an Outcome Measure based on Motivation and Action for Occupational Therapists working in Neurological Rehabilitation. 2018

“Action without vision is only passing time, vision without action is merely day dreaming, but vision with action can change the world”

Nelson Mandela and Joel A. Barker

ACKNOWLEDGEMENTS

I have a number of people to thank for assisting with this thesis:

- My supervisor, **Mrs Jodie de Bruyn** for all the guidance and encouragement throughout this process and for providing me with a platform to achieve my dreams.
- My co-supervisor, **Mrs Veronica Ramodike** for the valuable feedback and for challenging me to improve my own abilities as a researcher and my writing skills.
- The **occupational therapists** who participated in this study for the valuable information provided during the focus groups.
- **Dr Daleen Casteleijn** for assisting with arrangements regarding venues for focus groups.
- My colleagues and work family at Rehabworx, Life Groenkloof Hospital, but especially: **Nikki** for always believing in me even when I didn't believe in myself, challenging me to better myself (physically, emotionally, spiritually and academically) and providing me with a safe place to combat these challenges; **Jody** for the constant support and "brotherly" love; **Clarissa and Inge** for the support, encouragement and assistance in the tough times; and **Kirsten** for the many early morning gym sessions and sushi dates.
- My friends who supported me during this study, but especially: **Daniella** for our weekly trip to whatever restaurant had a special on, for my packed lunches and emergency dinners and for your never-ending friendship; **Leándi** for supporting me endlessly despite being half way across the world; **Christine** for all the prayers and for encouraging me to never give up and **Liz** for all the sushi, tea, encouragement and never-ending support.
- **My Phil** for being one of my greatest supporters, for proof reading some of this thesis, for the countless cups of tea, the many laughs, flights to and from Cape Town, four hour long telephone calls and endless love that you have shown me.
- My family for all the support, but especially; **Matt and Monique** for the countless prayers, support and encouragement; **Liz** for assisting with the organisation of some focus groups and always listening to my crazy OT ideas; and **my grandparents (Granddad, Nana and Ei)** for all the support, prayers and encouragement.

- A big thank you to **my Dad and Mom** for the love that you have shown me throughout my life, for encouraging me to be the best person I am able to be, for teaching me to always remain true to myself, giving me the opportunity to become an occupational therapist, always reminding me of my dreams, for the many visits to Pretoria to look after me, proof-reading and language editing this thesis and the countless number of other things you have given me. Without the two of you, I would not be where I am today. This thesis is dedicated to you!

TABLE OF CONTENTS

LIST OF ANNEXURES

LIST OF TABLES

TABLE OF FIGURES

CONCEPT CLARIFICATION

Assessment tool: An assessment tool aims to describe the effect of injury, illness, poverty, environmental factors and disability on an individual's participation in occupations.[1] In occupational therapy, an assessment tool is used at the beginning of treatment to determine an individual's functional abilities.[2]

Outcome measure: An outcome measure aims to describe the same factors as an assessment tool, as well as indicate the effectiveness of intervention.[1] An outcome measure is an instrument constructed in order to gather information regarding the efficacy of service/therapy programmes; a method of determining whether goals or objectives have been met.[3]

Acquired brain injury: An acquired brain injury (ABI) is damage to the brain that is acquired after birth. It can result from a non-traumatic brain injury, for example a cerebral vascular accident (CVA), or a traumatic brain injury (TBI), caused by for example a fall or a car crash. The damage can be diffuse or focal and the damage to the brain can range from mild to severe, which results in mild to more severe, long-term symptoms. An acquired brain injury can have extremely varied effects, with no two people presenting with the same symptoms or expecting the same outcomes. Deficits can fall under different categories, namely cognitive, motor/physical and social/personality changes.[4]

Neurological Rehabilitation: Rehabilitation is described by Barnes[5] as "a process of education of the disabled person with the ultimate aim of assisting that individual to cope with family, friends, work and leisure as independently as possible". Neurological rehabilitation falls into the following five categories[5]:

i. Patients who make spontaneous full recovery over a short time (mild CVA, seizure disorder)
ii. Patients who recover steadily and may or may not fully return to pre-morbid functioning (moderate CVA or TBI)
iii. Patients who will not improve much and who can also expect residual fallouts, but in whom progress is still a possibility (severe CVA or TBI)

iv. Patients with conditions that will deteriorate over time (multiple sclerosis, Parkinson's disease)
v. Patients whose condition will progress steadily and rapidly (motor neurone disease or malignant glioma).

Occupation: "Occupation is everything we do in life, including actions, tasks, activities, thinking and being".[6] It can therefore be noted that occupational therapists' definition of occupation is different from the layman's definition (work-related tasks). Collins Concise Dictionary[7] defines occupation "the act of occupying or the state of being occupied" and "any activity on which time is spent by a person".

Creative Ability: A term used in a Model developed by occupational therapist, Vona du Toit, the Vona du Toit Model of Creative Ability (VdTMoCA). Creative Ability is defined as "The ability to freely present oneself, without inhibitions, limitations or anxiety".[8] It also refers to an individual's preparedness to function at their maximum level of competence. An individual's creative ability is able to develop within the limits of the individual's creative potential within the optimal circumstances. The core belief of the Model is that a person's motivation determines their action and their action is the expression of their motivation.[8] The VdTMoCA divides Creative Ability into levels namely Tone, Self-Differentiation, Self-Presentation, Passive Participation, Imitative Participation, Active Participation, Competitive Participation, Contribution and Competitive Contribution. For this study the first six levels of Creative Ability will be investigated as these are the levels generally seen by occupational therapists. People functioning on higher levels generally possess the skills and knowledge to overcome everyday challenges, achieve norms and contribute to their communities.[9]

Activities of Daily Living (ADL) / Basic Activities of Daily Living (BADL): ADL's or BADL's are those activities that are directed toward caring for one's own body. This includes bathing or showering, bowel and bladder management, dressing, eating, feeding, functional mobility, personal device care, personal hygiene and grooming, sexual activity and toilet hygiene.[2] For the purpose of this study, the terms ADL and BADL will be used interchangeably.

Instrumental Activities of Daily Living (IADL): IADL's are those activities that support daily life within the community and home environments. They are more complex than self-care. IADL's include care of others (including the selection and supervising of caregivers), care of pets, child rearing, communication management, community mobility, financial management, health management and maintenance, home establishment and management, meal preparation and clean-up, religious observance, safety and emergency maintenance, as well as shopping.[2]

Domains: The range of concepts that is measured by an outcome measure e.g. health status, quality of life, activity participation and life satisfaction.[10] Domains included in this study are: motivation, action, quality of product/performance and task concept, relational contact with the body, relational contact with the social world, relational contact with tools and materials, control of anxiety and the ability to show initiative and make an effort.

Domain descriptors: For the purpose of the study, domain descriptors will refer to the information obtained during data collection, per level of Creative Ability and according to each domain set out in the research/outcome measure.

Rasch Measurement Model: A mathematical model developed by Georg Rasch, to convert ordinal scales into constant interval or linear measures.[1,11-15] Most occupational therapy assessment tools make use of ordinal scales, which results in difficulty using the information as an outcome measure. The conversion of ordinal scales into constant interval or linear measures provides therapists and researchers with information that can be used in the development of an outcome measure.

Themes: In qualitative research, the data obtained is analysed and grouped into different themes. For this study, themes are defined as a representation of patterned responses or codes grouped together to answer the research question. The themes obtained in this study are converted into the domain descriptors for the outcome measure being developed, through the review of literature.[16]

Substantiating codes: For the purpose of this study, substantiating codes are defined as the most relevant codes attached to a particular theme to allow for easier recognition of that attribute in a patient. This is to ensure that the themes are carried across effectively and to provide added meaning to the themes. Substantiating codes are often examples of behaviour related to the theme.

LIST OF ABBREVIATIONS

Abbreviation	Meaning
ABI	Acquired Brain Injury
ADL	Activity of Daily Living
APOM	Activity Participation Outcome Measure
BADL	Basic Activities of Daily Living
CPA	Creative Participation Assessment
CVA	Cerebral Vascular Accident
FLOM	Functional Levels Outcome Measure
IADL	Instrumental Activity of Daily Living
OT	Occupational Therapy
OTCAP	Occupational Therapy Creative Ability Programme
TA	Thematic Analysis
TBI	Traumatic Brain Injury
VdTMoCA	The Vona du Toit Model of Creative Ability

ABSTRACT

Motivation is a crucial determinant of the outcome of rehabilitation in patients following an ABI. Their level of motivation therefore requires close monitoring during assessment and treatment. Occupational therapists also require a way in which the effectiveness of their services can be measured. There is however a lack of an assessment tool or outcome measure specifically designed for the field of neurology that directly assesses a patient's level of motivation, while also including their occupational engagement.

The purpose of this study was to close this gap in neurological rehabilitation by developing an outcome measure that assesses a patient's motivation, while also addressing their corresponding action and therefore their engagement in occupations. The outcome measure had to be grounded in a theoretical framework that covers motivation and action. The Vona du Toit Model of Creative Ability (VdTMoCA) was chosen as the theoretical framework as it allows therapists to describe a patient's participation in everyday occupations according to their motivation and action. The Model provides therapists with a list of consecutive levels on which patients can function. This provides therapists with a means to measure baseline performance, track the progress of patients and calculate the effectiveness of intervention.

A qualitative research design was selected to guide this study. Two objectives were set for the development of the outcome measure. Domain descriptors for the outcome measure, according to the first six levels of Creative Ability, emerged to fulfil the first objective. This was achieved through the use of focus groups held with occupational therapists working in neurological rehabilitation. The design and development of the framework for the outcome measure and the transfer of the data into the measure was a theoretical process and fulfilled the second objective.

During data analysis, themes and substantiating codes emerged for all the domains within each level of Creative Ability. The themes that emerged for the domains "Motivation" and "Action" are as follows. In the level of Tone, "Motivation": motivationally blank, physiological maintenance; "Action": pre-destructive, reflexive and involuntary. In the level of Self-Differentiation, "Motivation": egocentric and to

differentiate self from the environment in order to establish body boundaries; “Action”: destructive, incidentally constructive and emergence of participation. In the level of Self-Presentation, “Motivation”: to present self, unsure and externally motivation; “Action”: Explorative, facilitated and 1-2 steps. In the level of Passive Participation, “Motivation”: directed to the attainment of skills and establishing rules and norms, externally motivated; “Action”: skill or product centred, therapist directed, safe and 2-4 steps. In the level of Imitative Participation, “Motivation”: intrinsically motivated to achieve something; “Action”: imitative, norm directed and 7-10 steps. In the level of Active Participation, “Motivation”: directed to the improvement of self; “Action”: with originality and transcends the norms.

The outcome measure that was developed was named the Motivation and Action in Neurological Rehabilitation Outcome Measure (MANROM).

Recommendations regarding the investigation of the psychometric properties were formulated to eventually market the MANROM as a reliable and valid outcome measure for occupational therapists in neurological rehabilitation.

CHAPTER 1 :
OVERVIEW OF THE STUDY

1.1 Introduction and background

Some of the core beliefs of occupational therapy as a profession are the relationship between occupation and health, as well as the profession's view of people as occupational beings.[2] According to Wilcock and Townsend,[17] "All people need to be able to or enabled to engage in the occupations of their need and choice, to grow through what they do and to experience independence or interdependence, equality, participation, security, health and well-being". For occupational therapists, "occupation" encapsulates everyday activity, in any walk of life (be it play in paediatrics, school, work, leisure, sleep etc.). For this reason, engagement in occupation is the focus of occupational therapy intervention and it includes both the patient's emotional and psychological aspects as well as physical aspects of performance. "Occupation" and "activity" are often used interchangeably within the profession.[2]

In order to promote health and well-being through the active engagement in occupations, occupational therapists follow a specific process – The Occupational Therapy Process.[2] Despite the explanation of this process in a linear manner, it is in fact a fluid, dynamic and ongoing process. This is also a collaborative process, with the occupational therapist, patient and family being actively involved in all steps.[2]

The process consists of three steps, namely evaluation, intervention and outcomes.[2]

i) Evaluation

The first step of the OT process consists of the occupational therapist conducting an evaluation of the patient. This evaluation is focused on determining what the patient and family want and need, determining what the patient is able to do as well as identifying what factors support or act as barriers to the patient's participation and health. During the evaluation, the occupational therapist conducts an occupational profile assessment (collecting personal information on the patient) and analyses occupational

performance (where the occupational therapist uses assessment tools in order to observe and measure the patient's occupational performance).[2]

ii) Intervention

The information gathered in the evaluation process is used in collaboration with theoretical principles in order to direct occupation-centred interventions. During this stage, intervention is provided to assist the patient to reach physical, mental and social well-being, to satisfy needs and to change or cope with their environment. The different types of occupational therapy intervention can be found in Table 1.1 below.[2]

Table 1.1: Type of intervention

Type of intervention	Explanation
Therapeutic use of self	The planned use of the occupational therapist's personality, perceptions, judgements and insights during the therapeutic process.
Therapeutic use of occupations and activities	The selection of occupations and activities that meet the therapeutic requirements of the patient.
Consultation	The use of knowledge and expertise to collaborate with the patient and family.
Education	The imparting of knowledge and information regarding occupation.
Advocacy	The promotion of occupational justice and the empowerment of patients to employ their own solutions to their daily occupations.

The intervention process is further divided into three steps, namely intervention plan, implementation and review. This study focuses on assessment and measurement of outcomes and therefore these steps will not be discussed further.[2]

iii) Outcomes

Outcomes are seen as the end result of the occupational therapy process and describe what the provided intervention achieved. These outcomes can include health, participation and engagement in occupation, which are predetermined by the collaborative efforts of the patient, family and therapist. In order to determine the patient's success in achieving these outcomes, occupational therapists assess observable outcomes. When selecting an appropriate measure, occupational therapists ensure that it is

in line with the patient's needs and wants, congruent with the occupational therapists' theoretical framework and based on the knowledge of the psychometric properties or rationale and protocol of the measure.[2]

The implementation of the outcome process includes two steps, namely[2]:

1. Selecting the types of outcomes and measures (occupational performance, health and wellness, adaptation, self-advocacy, prevention, occupational justice and quality of life).
2. Using the outcomes to measure progress and adjust interventions and goals.

As seen in the occupational therapy process, accurate assessment of the patient's emotional, cognitive and physical abilities and their occupations is an essential element in the effective delivery of occupational therapy services. In order to justify intervention and its effectiveness, occupational therapists also require a way in which their services can be measured, hence the need for outcome measures.[2]

The scope of the profession of occupational therapy encompasses a wide variety of conditions, populations and scenarios. In this study, the field of neurological rehabilitation will be discussed, with particular reference to acquired brain injuries (ABI's), which include but are not limited to cerebral vascular accidents (CVA's) and traumatic brain injuries (TBI's).

Occupational therapists play a crucial role in the rehabilitation of patients following an ABI. The focus of occupational therapy assessment and intervention following an ABI, is the enhancement of the patient's functional, physical and cognition abilities.[14,18]

Research however indicates that a patient's level of motivation following an ABI can affect their commitment and perseverance in treatment.[19] Anecdotal evidence and research indicate that motivation is a crucial determinant of the outcome of rehabilitation in patients following an ABI.[20] Low motivation can therefore impede their participation in therapy and their essential occupations (ADL etc.).

The Latin root of "motivation" can be directly translated as "to move". Therefore, in a basic way, the assessment of a patient's motivation is actually the assessment of

their action.[21] When studying the theories of motivation, it becomes evident that motivation leads to the decision to act and once the individual has engaged in the action, this motivation continues to play a role in determining whether or not the action is fulfilled.[21] A patient's level of motivation is therefore crucial in all aspects of occupation engagement and without it, initiation of tasks, execution of the steps involved and task completion are not possible.[21]

It is important to keep in mind the full range of clinical, social and psychological factors that influence the formation of motivation while assessing and treating patients.[22] Several studies support the notion that patient motivation is a strong determinant of rehabilitation outcome.[21-24] However O'Gorman[23] also stated that motivation is the "…most important, yet most difficult part of the work of the therapeutic professions…"[22-23] King and Barrowclough[24] found that rehabilitation professionals present with inconsistencies in what deems a patient "motivated' and "unmotivated" and therefore motivation is often left out of the assessment and treatment of neurological patients in rehabilitation. This neglect of motivation in the assessment and treatment process, results in a misunderstanding of the patient and their needs, an inability to provide holistic patient treatment and decreased rehabilitation outcomes.[24]

Participation in essential occupations can be seen as a result of motivation, patterns, environmental influences and performance capacity factors. The major focus of any occupational therapy assessment and treatment should therefore include the client-centred, holistic determination of a patient's level of motivation and action.[1,25] For a patient to feel success during rehabilitation, and therefore progress, the difficulty of the treatment tasks and interaction should match their current level of motivation and subsequent action. Bosman, van Heugten, Wilkens, Smeets and Visser-Meily[20] found that motivation following an ABI is an area that has received little attention in literature, with therapists mostly determining a patient's level of motivation informally or based on clinical judgement.

As seen above, appropriate and accurate assessment is an essential step in the occupational therapy process and without it intervention cannot be suited to the specific patient. Standardised instruments are known to aid in the effective assessment of patients and therefore a tool that accurately assesses a patient's level of motivation could assist occupational therapists in delivering client-centred treatment.[2]

There are a number of different assessment methods and outcome measures available to occupational therapists working in neurology, including self-report questionnaires, simulated environments, functional scales and collateral information sheets.[1] These will be discussed in further detail in Chapter 2. There is however a lack of an assessment tool or outcome measure specifically designed for the field of neurology that directly assesses a patient's level of motivation, while also including their action and occupational engagement.

A Model that was developed by Vona du Toit in 1972, named the Vona du Toit Model of Creative Ability (VdTMoCA), for assessment and treatment of spinal cord injuries, psychiatric patients as well as children, focuses specifically on patients' motivation and action.[8] The Model has received a lot of attention in the field of psychiatry, with assessment tools and outcome measures available in this field. The benefits of this Model have been noted in neurology, although minimal research has been conducted in this field.[1] Therapists working in neurological rehabilitation are therefore making use of the Model in a non-standardised way, in order to adapt its features to suit patients with ABI's. As a result, there is no consensus on the presentation of motivation and action in neurological patients, which impairs the trustworthiness and comparability of the assessment results.

The major focus of the Model is on the patient's participation in everyday occupations or activities. According to the Model, every person requires motivation in order to participate. The motivation discussed here is the inner force that directs the patient's behaviour and results in the creation of products (tangible or intangible), hence the term "Creative Ability".[1,8] The term "Creative Ability" refers to the person's ability to bring about change within themselves and their world – to bring into being something that did not previously exist.[1] The core belief of the Model is that a person's

motivation determines their action and their action is the expression of their motivation.[1,8] By observing the action of patients, a therapist can then infer the corresponding level of motivation. Figure 1.1 below provides a visual representation of the relationship between motivation and action.

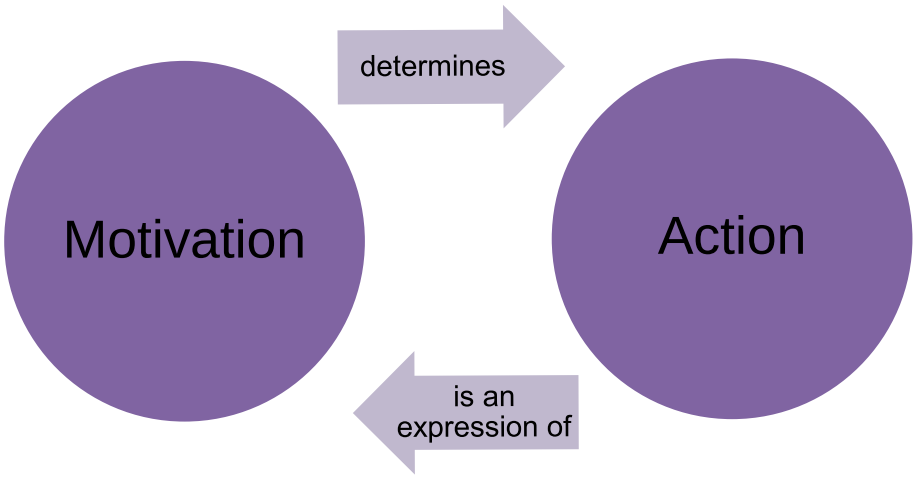

Figure 1.1: Relationship between Motivation and Action

From the above mentioned notions, du Toit[8] developed a hierarchy of levels of motivation which correspond to their levels of action. Casteleijn's research, which was conducted in the field of psychiatric occupational therapy to confirm the levels of Creative Ability, concluded that there is sound evidence that the different levels of Creative Ability do exist.[9]

Casteleijn also concluded that occupational therapists can make use of the Model and respective assessment tools and outcome measures with confidence, knowing that it provides a valid indication of the patient's limitations in everyday activities.[1] There are 9 levels of motivation and action in the VdTMoCA. These levels are sequential, with progression and regression through the stages being possible.[1] Table 1.2 below indicates the 9 levels of motivation with their corresponding action.[8]

Table 1.2: Levels of Motivation and Action

	Level of Motivation	Action
1	Tone	Pre-destructive, purposeless action
2	Self-Differentiation	Destructive/incidentally constructive action
3	Self-Presentation	Explorative action
4	Passive participation	Norm awareness, passive participative action
5	Imitative participation	Norm-compliant, imitative action
6	Active participation	Individualistic participative action
7	Competitive	Competitive-centred action
8	Contribution	Situation-centred action
9	Competitive participation	Competitive product centred action

Since the patients can be classified from as low as having no response or awareness of their environment, the Model allows therapists to implement therapy from "Day one", with patients who previously may have been deemed too unwell to receive occupational therapy services (patients on a level of Tone according to VdTMoCA).[8]

As previously mentioned, determining and measuring outcomes is a major part of the occupational therapy process. Most occupational therapy assessment tools are on an ordinal scale, which inhibits the interpretation of data, due to unequal distances between points.[1] Data on a level three, namely an interval scale, can be used as a measure of outcome as the intervals between each category are equal.[1]

Casteleijn,[1] in her study which aimed to confirm the levels of Creative Ability, used the Rasch measurement model to assess the hierarchical nature of the levels of Creative Ability. The Rasch measurement model can convert ordinal type of measurements into interval/linear measures.[1] Casteleijn concluded that the levels of Creative Ability fit Rasch's model well and the data could therefore be successfully converted to interval measures. Casteleijn's study concluded that the levels of Creative Ability can be used as a reliable outcome measure in occupational therapy.[1,11-15]

Following trauma, illness or injury, patients tend to regress to a lower level of functioning/ability, thereby deeming the VdTMoCA applicable to all patients in all spheres of occupational therapy.

An outcome measure developed according to the VdTMoCA in neurological rehabilitation can be used to determine a patient's level of motivation and action, indicate effectiveness of intervention and provide principles of treatment. Due to the extensive research already conducted in the field of psychiatry, this study aims at building on the already available research, while expanding the research into the field of neurology.

1.2 Problem statement

Assessment of patients' participation in occupation, as well as measuring the effectiveness of treatment is core to the process of occupational therapy.[1] Wilcock[25] states in his theory of human need for occupation, that occupation is central to the human experience. It is therefore essential for occupational therapists to understand individuals as occupational beings as well as what their needs and expectations regarding occupational therapy are. Occupation can be seen as a result of motivation, patterns, environmental influences and performance capacity factors. The Latin root of "motivation" can be directly translated as "to move". Therefore, in a basic way, the assessment of a patient's motivation is actually the assessment of their action.[21] The major focus of any occupational therapy assessment should therefore include the determination of a patient's level of motivation and action.[1]

Research indicates that a patient's motivation following an ABI can affect their participation in occupations and influence the outcomes of their rehabilitation and is therefore a crucial element to be considered in the assessment and treatment of patients following an ABI.[21]

Occupational therapists in neurological rehabilitation have several assessment tools and outcome measures available.[5] It has however been noted that popular client-centred assessments such as the Canadian Occupational Performance Measure (COPM)[26] rely on the patient's ability to make decisions and judgements.[1] Following neurological trauma, patients experience regression in many aspects of their lives, including basic cognitive abilities, therefore impeding their ability to make decisions and judgements.[27-28] There is also a lack of an assessment tool or outcome measure specifically designed for the field of neurology that directly assesses a patient's level of motivation, while also assessing their occupational engagement.

A Model that was developed by Vona du Toit[8] focuses specifically on the motivation and action of patients. The Model has received a lot of attention in the field of psychiatry, with assessment tools and outcome measures available in this field. The benefits of this Model have been noted in the field of neurology, although there is minimal research available in this field.[1] This has resulted in occupational therapists working in neurology making use of the Model and therefore applying the principles of assessment and treatment laid out in psychiatry as best as possible, without set guidelines in neurology. These therapists therefore make use of clinical reasoning and subjective observations in order to determine the level of motivation and corresponding action of their patients, which in turns makes these results subjective and untrustworthy.

There is therefore a lack of an outcome measure that can be used to determine the level of motivation and action of adults with neurological conditions.

1.3 Significance of the study

The development of assessment tools and outcome measures based on the VdTMoCA, with particular reference to the Activity Participation Outcome Measure (APOM) - refer to Table 2.3 for more information on the tool - provides a strong baseline and starting point for further research on the VdTMoCA in a variety of different fields of occupational therapy.[29] This study therefore builds on the already developed tools with the new focus on neurological rehabilitation.

The true value of this study is therefore to provide occupational therapists with an outcome measure that can be used in the field of neurology, to successfully assess and treat patients according to their specific level of motivation and action using principles from the VdTMoCA. The outcome measure developed in this study will also, following further research on the validity of the measure, validate the effectiveness of treatment provided. The outcome measure can be used daily, in every assessment conducted, through observing patients in different settings. The outcome measure developed in this study therefore aims to not be as comprehensive and lengthly to administer as the APOM to ensure that therapists can make use of the measure in daily occupational therapy assessment and treatment.

The outcome measure provides therapists with constant-interval or linear, measurable data to include in reports written to other health professionals, medical aids and family members etc., indicating the effectiveness of the treatment delivered. This information can also be used in motivating the need for occupational therapy in neurological rehabilitation, within the private sector, public sector and non-profit organisations. The outcome measure can also assist in providing therapists with more effective discharge planning by bringing to the therapists' attention the patients' level of motivation and action. If the patient is functioning on a low level of motivation and action, family and caregiver training will be the focus of discharge planning to ensure that home programmes are followed and medication is managed. Patients with a higher level of motivation and action can be given more responsibility for their own rehabilitation and medical management.

Since five out of the eight universities in South Africa study the VdTMoCA at undergraduate level, the results obtained from using the outcome measure will be widely understood amongst therapists and thus increase the likelihood of its use in practice.[11]

1.4 Research question

What are the domain descriptors for a VdTMoCA-based outcome measure for occupational therapists working in neurological rehabilitation that successfully assesses a person's motivation and action?

1.5 Research aim and objectives

The aim of the research was to determine the domain descriptors per level of Creative Ability according to each domain specified, for a VdTMoCA-based outcome measure for occupational therapists working in neurological rehabilitation to successfully assess a patient's motivation and action. To achieve this aim, the following objectives were developed:

- Objective 1: To develop domain descriptors for each of the first six levels of Creative Ability.
- Objective 2: To develop and design a user-friendly outcome measure using the information gathered in the first objective.

1.6 Frame of reference

A social constructivism approach was used during the process of this study.[30-33] In this approach, individuals seek an understanding of the world in which they work and live.[30-31,33] The individuals develop subjective understandings of their experiences (directed toward specific objects). It is believed that the meanings individuals develop are varied and multiple which results in the researcher looking for the complexity of views instead of the narrow meaning of a few ideas or categories.

In terms of practice, the approach indicates that questions should be broad and general so as to allow the participants to construct the meaning of a situation (through discussions and interactions with others).[30-31,33] This approach was used while working towards the first objective of this study, during the focus groups. In this approach, it is important for the researcher to recognise that their background shapes their interpretations. It was therefore important that the researcher positioned herself appropriately in the study and acknowledged how her interpretation would flow from her own experiences.[30-31,33] The following assumptions were applicable to the study according to the social constructivism approach.

1.6.1 Ontological assumptions

During the focus groups, it was noted that each participant brought their own views of the world to the study and this was respected through open questions and discussions. These different perspectives were reported back in the form of codes and themes.[30-31,33]

1.6.2 Epistemological assumptions

The use of focus groups allowed each participant to bring their own views to the discussion and the dynamics of the group process allowed the views to complement and expand on each other. Reality was therefore co-constructed by the researcher and participants.[30-31,33]

1.6.3 Axiological assumptions

The social constructivism approach is value conscious. During focus groups, individuals' values were honoured and negotiated amongst the participants in the group. The researcher acknowledged that bias can be present during the groups and realised the need for a larger number of participants over a few focus groups.[30-31,33]

1.6.4 Methodological assumptions

During the focus groups, an inductive method of emerging ideas was used by means of obtaining consensus on ideas discussed. Textual analysis with verbatim transcription of the information that emerged during the focus groups was also conducted.[30-31,33]

1.7 Delineation

The researcher delineated the study in the following ways:

- Only occupational therapists currently practicing or lecturing in neurology were included in the focus group in order to ensure reliable, focused discussions.
- Due to logistical reasons, only therapists in the Gauteng Province in South Africa were invited to participate in the focus groups.
- The outcome measure only includes the first six levels of the VdTMoCA (Tone to Active Participation) as patients do not generally function on a higher level than this while actively receiving therapy.
- This study did not test the validity, reliability or sensitivity of the outcome measure.

1.8 Concluding remarks

This chapter provided an overview of the study. A background to neurological occupational therapy and an overview of the VdTMoCA were given. The problem statement which resulted in the research question was laid out, as well as the research aims and objectives. A summary of the significance of this study and the benefit the results can bring to the neurological occupational therapy profession were described.

The lack of research available on the use of the VdTMoCA in neurological occupational therapy was discussed in this chapter. An outcome measure based on motivation and action is of crucial importance in the holistic treatment of neurological patients. The need to develop a tool that will provide occupational therapists with a comprehensive means of assessing their patient's level of functioning, measure efficacy of treatment delivered and assist with discharge planning was discussed.

The following chapters will review the current literature relevant to this study, outline the research design and methodology, discuss the research findings, state the conclusion and lastly make recommendations regarding further research on this topic.

CHAPTER 2 :
LITERATURE REVIEW

2.1 Introduction

In the preceding chapter, an overview and introduction to the study was given. The aim of this chapter is to provide an in-depth look at the topic under study. This is done by reflecting on the literature that is available and was reviewed.

According to Randolph,[34] a literature review is conducted as a means of demonstrating the researcher's knowledge regarding the topic under study. It also informs the researcher and the reader of the influential researchers and research groups in the field of study.[34] A literature review is also conducted for the following reasons[34]:

- To report on ideas and knowledge that have already been established on the particular topic, including the strengths and weaknesses
- To identify and resolve contradictions between various contributions and determine gaps in the research
- To justify the study's choice of research design
- To clarify how the study will fill a gap in the literature

This chapter outlines available research in this field of study, identifies the gap in the research and necessitates the development of an outcome measure based on motivation and action for occupational therapists in neurological rehabilitation. Firstly, neurology is discussed to give an overview of the implications of a neurological insult. Secondly, occupational therapy in the field of neurology is explained, with a focus on the assessment and treatment of patients who have suffered a CVA or TBI. Thirdly, outcome measures and assessment tools within occupational therapy are explored with an emphasis on their appropriateness for use in neurology and their inclusion of the assessment of motivation. Fourthly, the Vona du Toit Model of Creative Ability is discussed in detail, with its application in psychiatry and the benefits noted in other fields of occupational therapy. The researcher then discusses the psychometric properties of the VdTMoCA determined by Casteleijn, with particular reference to the Model's use as an outcome measure. The chapter concludes by discussing models

and scales available to health professionals working with patients who have suffered an ABI.

2.2 Neurology

The field of neurology is broad, covering a variety of conditions affecting a patient's brain including cerebral vascular accident (CVA), traumatic brain injury (TBI), multiple sclerosis (MS) and brain tumours, to name a few.[35] Research indicates that low motivation is a frequently observed phenomenon in patients who have suffered an acquired brain injury (ABI).[20] For this reason, this study will focus on the presentation of patients following an ABI.

An ABI is damage to the brain that is acquired after birth. It can result from a non-traumatic brain injury (for example a CVA) or a traumatic brain injury (caused by for example a fall or a car crash). The damage can be diffuse or focal and the damage to the brain can range from mild to severe which results in mild to more severe long-term symptoms. An acquired brain injury can have extremely varied effects with no two people presenting with the same symptoms or expecting the same outcomes. Deficits can fall under different categories, namely cognitive, motor/physical and social and personality changes.[4] Cognitive deficits include memory problems, concentration problems, perceptual deficits and problem solving deficits to name a few. Motor/physical fallouts include but are not limited to paralysis or spasticity, visual fallouts (neglects) and communication problems (aphasias). In terms of social and personality deficits, difficulty understanding and responding to social interactions, as well as self-centredness and decreased motivation may be present. Other personality changes can include decreased motivation, irritability, anxiety and depression.[4] As this study focuses on the motivation of patients following an ABI, the theme of decreased motivation is discussed in more detail.

Literature reports that patients with right hemispheric CVA's present with the indifference reaction. Babinski as well as more recent authors have described this as patients who show a lack of emotion, inappropriate cheerfulness and poor motivation.[19,36-37] Literature also indicates that a patient's motivation is severely impaired following a CVA that affects the amygdala and anterior temporal lobes of the brain.[38] This lack of motivation is also a dominant symptom in ABI's affecting the

frontal lobe of the brain.[39] On top of these anatomical insults, literature indicates that social (lack of a support structure etc.) and personality factors (intrinsic motivation) can also influence a patient's motivation post-ABI.[22]

Specialists in ABI rehabilitation have long suspected that motivation is a crucial determinant of the recovery of patients following an ABI and this has been confirmed in numerous studies.[22,24,39]

The effect of all of the above mentioned impairments, together with environmental barriers, leads to occupational dysfunction or disability which is an inability to independently engage in meaningful occupations.[14-15] Despite the fact that the functional outcome or recovery following an ABI depends largely on the severity and nature of the injury, appropriate treatment at the appropriate time plays a crucial role in determining the level of recovery.[4] The outcome is best if the approach is multi-disciplinary, including doctors, nursing staff, family, dietician, psychologist, social worker, physiotherapist, speech therapist and occupational therapist.[4]

2.3 Occupational therapy in neurology

The rehabilitation of a patient following an ABI aims to improve the patient's physical abilities and mobility, teach the use of assistive devices for activities of daily living (ADL), train practical skills, improve cognition, reintegrate into work and society and assist patients to accept or adapt to their losses. Occupational therapists play a crucial role in rehabilitation following an acquired brain injury. The focus of their assessment and treatment is on the patient's functional abilities in their ADL and instrumental activities of daily living (IADL), i.e. returning to previous occupations.[14,18]

Research however indicates that a patient's motivation following an ABI can affect their commitment and perseverance in treatment. Anecdotal evidence and research indicate that motivation is a crucial determinant of the outcome of rehabilitation in patients following an ABI.[20] Low motivation can therefore be seen as impeding their participation in therapy and their essential occupations (ADL etc.). Participation in essential occupations is seen as a result of motivation, patterns, environmental influences and performance capacity factors. The major focus of any occupational therapy assessment and treatment should therefore include the client-centred,

holistic determination of a patient's level of motivation and action.[1] This is reiterated in Wilcock's[25] theory of human need for occupation when the author states that occupation is central to the human experience.[25] For a patient to feel success during rehabilitation and therefore progress, the grading of treatment and interaction should match their current level of motivation and functioning. On top of the appropriate grading of treatment tasks (e.g. increasing or reducing the complexity of a task), therapists should also be sensitive to the ways in which social and intrinsic personality factors have an effect on the patient's motivation.

Literature on the study of the social and intrinsic personality factors that influence motivation suggest the following rehabilitation practices in order to positively impact on the patient's motivation[22,24,39]:

- Setting of clear and revisable goals
- Acknowledging of the patients views
- Avoiding the clashing of views
- Being seen as warm, approachable and competent
- Including nursing staff in therapy
- Including the family in therapy (as good social and community support assist in motivating patients)
- Avoiding the placement of the responsibility for motivation and recovery solely in the hands of the patient

Despite the array of literature available on the effects of motivation in rehabilitation, Bosman, van Heugten, Wilkens, Smeets and Visser-Meily[20] found that there is a lack of literature on ways of effectively measuring or assessing a patient's motivation following an ABI. As a result, therapists mostly determine a patient's level of motivation informally or based on clinical judgement. Standardised instruments are known to aid in the effective assessment of patients and could therefore assist therapists in the assessment of motivation in patients following an ABI.[20]

There are a number of different assessment methods and outcome measures available to occupational therapists working in neurology including self-report questionnaires, simulated environments, functional scales and collateral information sheets.[1] These will be discussed in further detail in the following section.

2.4 Outcome measures in occupational therapy

Occupational therapists as a whole, and in the field of neurology, find it difficult to provide convincing evidence of their unique contribution to a patients improved functioning. Through the use of activities/occupations, to the untrained, uneducated eye, what occupational therapists do appears to be simple tasks or activities. The occupational therapist is however employing professional skills (clinical reasoning, therapeutic relationship, activity analysis, grading of activities and the environment) before deciding on and making use of the seemingly “simple” tasks.[29] Despite anecdotal feedback indicating that patients, families and team members do recognise the unique contribution of the occupational therapist within the team, this is hardly evidence enough to convince employers and new users of the true benefit of occupational therapy.[29] What occupational therapists therefore need is an objective measure to indicate the therapeutic outcomes of their intervention. Hence the development of an outcome measure in neurological rehabilitation. This is then linked to the above mentioned information regarding motivation and corresponding occupation and action being a core aspect of occupational therapy assessment and treatment.

When studying the array of outcome measures currently available to occupational therapists, it is evident that there are a number of measures that have been developed and tested. Here follows a summary of the measures available to neurological occupational therapists.

2.4.1 The Barthel Index

The Barthel Index (BI) was developed around 1955 in the United States of America. It was initially described as a tool that scores a patient's functional improvement throughout the rehabilitation process.[40] The original ten item BI scored patients' independence in feeding, grooming, toilet transfers, wheelchair transfers, walking, bathing, dressing, stair climbing and bowel and bladder continence. There were initially only two categories into which a patient could fall, namely "with help" or "independent". The score for this measure was out of 100.[40] In the 1980's, Shah et al. developed and published a modified version of the original BI, with the score for this measure being out of 20.[41] The purpose of this modification was to improve the sensitivity of the BI as well as introduce more categories and include a ranking system for the need of assistance. This version is known as the Modified Barthel Index (MBI).[41] The BI and MBI were developed for physically injured patients, although they do not incorporate the essential element of motivation into assessments findings. The BI and MBI also do not incorporate any aspect of cognition into assessments and therefore, if used independently in the rehabilitation of patients following an ABI, fail to look at the patient holistically.

2.4.2 Canadian Occupational Performance Measure

In the 1970's and 1980's a movement in the field of occupational therapy was established to reinforce the importance of occupation in this field[26] (for the purpose of this study, this movement will be referred to as the "the movement in occupational therapy"). This led to the development of a number of occupation-focused frameworks and models. One of these models is the Canadian Occupational Performance Measure (COPM), described below. The COPM was designed according to the Canadian Model of Occupational Performance (CMOP).[26]

The COPM was one of the first measures that was designed to measure changes after therapy.[26] Developed in the early 1980's, this tool assesses a patient's self-perceived ideas regarding their performance and satisfaction in daily occupations. The COPM is administered in the form of a semi-structured interview which is used in conjunction with the occupation-focused, client-centred Canadian Model of Occupational Performance. The tool covers the areas of self-care, productivity and

leisure (which includes social participation). Due to the client-centeredness of the measure, where the patient is required to identify their concerns regarding their functioning, it is essential that a comprehensive assessment of the patient's cognitive abilities be done prior to conducting the COPM.[29] The client-centeredness of this measure raises a point of concern for its effective use in neurological rehabilitation because, following an ABI, patients can experience regression in many aspects of their lives including physical abilities, psychological functioning as well as basic cognitive abilities. This results in patients finding it difficult to make decisions and judgements. Self-reporting could therefore be difficult and unreliable in cases where the patient's insight and cognition is affected.

2.4.3 The Assessment of Motor and Processing Skills

The Assessment of Motor and Processing Skills (AMPS) was also developed in the 1980's. Much like the COPM, the AMPS was developed due to the increasing need for occupational therapy-specific outcome measures.[29] The AMPS is used to measure the quality with which a patient performs familiar ADL's. The quality of performance is measured in terms of physical effort, safety, independence and efficiency. The OT administers the AMPS by observing the patient while performing two familiar, relevant ADL tasks. It is important that this occurs in a natural, task-relevant environment. The performance is scored according to the quality of 36 performance skills enacted during the task. Software is then used to generate results and measures.[42] Research by Chard[42] indicates that the AMPS is able to measure the changes in a patient's occupational performance in a number of clinical settings. Difficulties reported include the time to complete the AMPS and getting started. The AMPS could be seen as appropriate in the neurological rehabilitation field in terms of a patient's participation in ADL tasks and their physical functioning however, like the COPM, the measure fails to incorporate the essential element of motivation into the assessment findings which, as indicated in the previous discussion, is a fundamental aspect in the recovery of patients following an ABI.[42]

2.4.4 The Disability rating scale

The Disability Rating Scale (DRS) was developed in 1982 and tested for use in older juvenile and adult rehabilitation following traumatic brain injuries, within the inpatient setting. The measure addresses all three World Health Organisation categories, namely impairment, disability and handicap.[43] The first three items of the measure (eye opening, communication ability and motor response) reflect the impairments rating. Cognitive abilities required for feeding, toileting and grooming reflect the patient's level of disability. The "Level of Functioning" item reflects handicap, with the last item being "Employability". The patient can score on a scale from 0 (no disability) to 29 (extreme vegetative state).[44]

The advantages of the measure are that it can be administered quickly via interview or observation in one or two simple tasks and can be tracked throughout the recovery of the patient, from within the hospital (comatose state) to the return to work.[44] The measure however does not include crucial cognitive aspects affected by ABI's, namely problem solving, insight and executive functioning. It includes only a brief section regarding crucial occupational performance areas such as leisure and IADL's. The measure once again does not incorporate the essential element of motivation into the assessment findings.

2.4.4.1 The Functional Independence Measure and Functional Assessment Measure

The Functional Independence Measure (FIM) is a universal measure of disability that was developed in 1983.[45] It can be scored independently or with the additional 12 items that constitute the Functional Assessment Measure (FAM) which was added in the early 1990's. The FIM + FAM are designed for measuring disability in the acquired brain injury population. The measure has an ordinal scoring system for the 30 items from 1-7 (1 = complete dependence and 7 = fully independent). The measure was designed to be conducted only twice, the initial assessment being within ten days of the admission date to hospital and the second assessment being within seven days of discharge from hospital.[45]

The disadvantages of using the FIM + FAM is that the assessment requires the input from the whole multidisciplinary team, requires formal training and takes a long time to complete as the patient is to be observed performing all the tasks stipulated to score on the item (no predicted scores can be given). The measure also lacks critical occupational performance areas (including work, leisure and IADL). The measure fails to incorporate the essential element of motivation into the assessment findings which, as previously seen, is a fundamental aspect in the recovery of patients following an ABI.[45]

2.4.5 The Mayo-Portland Adaptability Inventory

The Mayo-Portland Adaptability Inventory (MPAI) was developed in the 1990's. The latest edition, namely the MPAI-4, was based on this original version and developed in 2004.[46] The MPAI-4 was designed to evaluate patients with ABI's during the post-acute phase (post-hospitalisation). The items of the MPAI-4 represent a range of physical, cognitive, emotional, behavioural and social problems that patients may suffer post-ABI. The measure also assesses major obstacles to community reintegration. The measure can be administered by therapists, doctors, nurses, the patients themselves or family members. The latest edition splits the categories into three subscales, namely Ability Index (sensory, motor and cognitive abilities), Adjustment Index (mood and interpersonal interactions) and Participation Index (social contacts, initiation and money management).[41] The disadvantages of this measure are the length that the assessment takes to complete and the fact that the measure is based on out-of-hospital patients. It therefore does not cover low functioning patients.[46] The measure also does not specifically address the essential element of motivation which, as previously discussed, is a crucial aspect to take into consideration post-ABI.

2.4.6 The Pate Environmentally Relevant Program Outcome System

The Pate Environmentally Relevant Program Outcome System (PERPOS) was developed in the mid-1990's by a multidisciplinary team.[47] The measure was developed to focus on the complex interactions of a patient's functional ability and the environment, rather than relying on the ability ratings without environmental context. Numeric values are allocated to the patient's overall functioning from 1 – 7, (with higher numbers indicating a larger degree of independence). Level of distraction within an environment is scored from 1-4 (with higher numbers indicating more distractions). Structure is also rated on a scale of 1-4 (with higher numbers indicating a lower level of external structure required). The overall functioning score is obtained using a seven-point scale (with higher scores indicating a higher level of functional ability) across a number of domains, namely mobility, basic ADL's, higher level ADL's, insight, communication and medical insight.[47]

All scores are related to the environmental circumstances within which they occur. The assessment is comprehensive and also lengthy to administer. The measure does not incorporate the essential elements of motivation into the assessment and is difficult to administer due to the need for computer-based systems and calculations.[47]

2.4.7 The Model of Human Occupation Screening Tool

The Model of Human Occupation Screening Tool (MOHOST) was initially developed in 2004 and revised in 2006, however it is based on the Model of Human Occupation which is also linked to the movement in occupational therapy in the 1970's and 1980's.[48] This tool, which was initially designed for the mental health setting, is based on the concepts defined in the Model of Human Occupation (which addresses motivation, performance as well as organisation of occupational behaviour). Despite the tool's name, it has been used as an outcome measure by therapists in a variety of settings.[48] The tool has six sections, namely motivation for occupation, pattern of occupation, communication and interaction, motor skills, process skills and the environment.[48] It is based on the premise that occupational performance is central to well-being. The tool is standardised and specific to mental health care users and has had little to no research done in the neurological field of occupational therapy. Therefore, much like the COMP and AMPS, it cannot be used with confidence in the

neurological rehabilitation setting. It should also be noted that the MOHOST is reportedly difficult to repeat regularly due to its lengthy observational requirements in specific ADL tasks. It also requires specific set-up and environmentally appropriate tasks for the patient.[48]

2.4.8 The Australian Therapy Outcome Measure

The Australian Therapy Outcome Measure (AusTOMs) was developed by Perry et al. in 2011.[49] This measure focuses on multidisciplinary outcomes in speech therapy, physiotherapy and occupational therapy. The occupational therapy outcomes include: (i) Learning and applying knowledge, (ii) Self-care, (iii) Functional walking and mobility, (iv) Domestic life: inside house, (v) Upper limb use, (vi) Domestic life: outside house, (vii) Carrying out daily life tasks and routines, (viii) Interpersonal interactions and relationships, (ix) Transfers, (x) Work, employment and education, (xi) Using transport, (xii) Community life, recreation, leisure and play.[49] The tool is comprehensive, with appropriate headings for use in neurology, although it relies heavily on a multidisciplinary team to administer fully which is not always applicable in South African contexts due to a shortage of multi-disciplinary staff members in some institutes. The tool also lacks critical occupational performance areas. The measure fails to incorporate the essential element of motivation into the assessment findings which, as previously discussed, is a fundamental aspect in the recovery of patients following an ABI.[29,49]

A table comparing the core aspects of the outcome measure above can be found in Table 2.1. It is evident that there is a lack of academic research into outcome measures that combine motivation and action in the field of neurology for patients following an ABI in the acute and chronic stages.

Table 2.1: Comparison of the outcome measures available

Tool	Neurology specific	Motivation and Action	Training, software required	Aspects covered in the tool		
				Physical/ Functional	Cognitive	Social/ Emotional
BI, MBI	Yes	No	No	Yes	No	No
COPM	No	No	No	Yes	No	Yes
AMPS	No	No	Yes	Yes	No	No
DRS	Yes	No	No	Yes (minimal)	Yes (minimal)	Yes (minimal)
FIM+FAM	Yes	No	Yes	Yes	Yes	Yes
MPAI-4	Yes	No	No	Yes	Yes	Yes
PERPOS	Yes	No	Yes	Yes	Yes	Yes
MOHOST	No	Yes	No	Yes	Yes	No
AusTOMs	No	No	No	Yes	Yes	Yes

Many occupational therapists in neurological rehabilitation (in South Africa and the United Kingdom particularly) have noted the benefits and make use of the Vona du Toit Model of Creative Ability (VdTMoCA).[8,50] This Model incorporates both motivation and action but has mainly been researched in the psychiatric field of occupational therapy. In order to understand the Model and its possible use in neurology, the Model and its components are discussed in more detail below.

2.5 Vona du Toit's Model of Creative Ability

2.5.1 Introduction to the Model

The Model, developed by Vona du Toit in 1972, was initially developed for the assessment and treatment of patients with spinal cord injuries, psychiatric patients and children.[8] The major focus of the Model is on the patient's participation in everyday activities/tasks. According to the Model, every person requires motivation in order to participate. The motivation discussed here is the inner force that directs the individual's behaviour and results in the creation of products (tangible or intangible), hence the term "Creative Ability".[1,8] The term "Creative Ability" refers to the person's ability to bring about change within themselves and their world, to bring into being something that did not previously exist.[8] The core belief of the Model is that a person's motivation determines their action and that their action is the expression of their motivation.[1,8] By observing the action of patients, a therapist can then infer the corresponding level of motivation. From the above mentioned notions, du Toit developed a hierarchy of levels of motivation which correspond to their levels of action. There are 9 levels of motivation and action in the VdTMoCA. These levels are sequential, with progression and regression through the stages being possible.[1] The

levels of motivation and their corresponding action can be found in Table 1.2, ranging from Tone to Competitive Participation.

Research indicates that therapists see patients ranging from the level of Tone to Active Participation, because if the individual is functioning on a level higher than this, they are generally deemed independent and a contributor to society and therefore discharged from therapy.[29] A brief description of the first six levels of Creative Ability can be found in Table 2.2.[8]

Table 2.2: A brief description of the first six levels of Creative Ability

Level of Creative Ability	Summary
1) Tone	• Motivation is aimed at the will to live (biological systems). • They are defenceless, incapable and dependent.
2) Self-Differentiation	• The patient's action is directed at establishing and maintaining self-awareness as a separate unit from the environment, objects and people in it. The patient's action can be either one of the following: • **Destructive action** Primitive interaction with the world. It is directed at defining their body boundaries and to practice basic skills. • **Incidentally constructive action** Unplanned, unintentional, constructive action. The action results by chance in an immediate, recognisable end product.
3) Self-Presentation	• The patient's action is directed at the presentation of self to others. It is also directed at developing the most basic and fundamental skills in social interaction. • Exploring their abilities (of their body, to control the environment and to be constructive).
4) Passive Participation	• The patient's motivation is aimed at establishing the rules and acceptable norms. It is goal directed. • They are unable to initiate tasks independently. • The patient is able to sustain interest in an activity that is structured and initiated by others. • Their emotions are more refined.
5) Imitative Participation	• The patient's action is predominantly aimed at complying with the norms. • Individuality is observable, but this requires a group/someone else who can imitate. • Motivation is product centred. Little evidence of initiative. Reluctant to compete and compare with others. • They are stressed by the unknown (where the norm is unclear).

Level of Creative Ability	Summary
6) Active Participation	• The patient's motivation is aimed at improving or changing aspects of activity/behaviour that they have noticed as a problem. Improvement is based on their personal egocentric needs. • Able to show initiative, original thought and start developing an ability to think broadly.

Once an assessment has been conducted to determine a patient's level of functioning, treatment can be administered to elicit participation and motivation with the aim of facilitating growth to the higher level of Creative Ability. The Model provides therapists with the means to conduct an assessment to determine a patient's level of Creative Ability and provides therapists with a detailed guide to the selection of treatment tasks, the structuring of the environment and the therapeutic use of self. When this is done, the selected activity provides the patient with the "just right challenge", as termed in the Model, which facilitates participation and growth.[8]

Since patients can be classified from as low as having no response or awareness of their environment, the Model allows therapists to implement therapy from "Day one", with patients who previously may have been deemed too unwell to receive occupational therapy services (patients on a level of Tone according to VdTMoCA).[8]

Since the Model's development, it has been researched in the psychiatric field of Occupational Therapy.[1,8,11] Several successful psychiatric assessment tools and outcome measures have been developed. These assessment tools and outcome measures include the Creative Participation Assessment tool (CPA),[1,51] the Functional Levels Outcome Measure (FLOM)[1,52] and the Activity Participation Outcome Measure (APOM).[29] A brief description of each of the above mentioned tools can be found in Table 2.3 below.

Table 2.3: Description of currently available VdTMoCA assessment tools and outcome measure

Creative Participation Assessment tool (CPA)[1,51]
• Developed for psychiatric patients • Seven-point scale with 12 items • Covers levels from Tone to Competitive Participation • Domains include: motivation, action, volition, handle tools and materials, relate to people, handle situations, task concept, product, assistance/supervision required, behaviour, norm awareness, anxiety and emotional responses and initiative and effort. • Observable description under each domain • Therapists tick most appropriate responses and tally these ticks at the end to determine which level the patient is functioning on
Functional Levels Outcome Measure (FLOM)[1,52]
• Developed for psychiatric patients • Ten items • Covers levels from Tone to Imitative Participation • Domains include: mental illness, orientation, self-care, appearance, contingency, social behaviour, activity participation, domestic skills, responsibility and employment potential. • Therapists mark the appropriate level for each domain and tally these marks at the end to determine which level the patient is functioning on
Activity Participation Outcome Measure (APOM)[29]
• Developed for psychiatric patients • Contained 18 points (including each of the three phases for each level) • Covers levels from Tone to Active Participation • Domains include: process skills, communication/interaction skills, life skills, role performance, balanced lifestyle, motivation, self-esteem and affect. • Each domain contains a description for each level • Therapists decide which description best fits the patient and then which phase the patient is functioning in • One day of training is required before therapists can make use of the APOM

The Occupational Therapy Creative Ability Programme (OTCAP), an assessment tool and programme developed and presented by du Toit, was developed to guide the assessment and treatment of paediatric patients/clients. A summary of the programme can be found in Table 2.4 below.[8]

Table 2.4: A summary of the Occupational Therapy Creative Ability Programme

Occupational Therapy Creative Ability Programme (OTCAP)[8]
• Developed for paediatric patients • Covers levels from Tone to Competitive Participation • Domains include: motivation, action, quality of product, relational contact with tools and materials, relational contact with people, relational contact with situations, control of anxiety, ability to show initiative, ability to make an effort. • Observable description under each domain • Guidelines for treatment per level include detailed descriptions of: treatment aims (according to their presentation on that level under each domain) and methods of presenting the treatment (the area, therapist approach and method).

Each level is linked to domains, each with a description of an observable behaviour. The domains used in the above mentioned outcome measures and assessment tools differ according to the purpose of the tool and according to factors determined through academic research. The domains used in the different tools are listed in Table 2.5 below.

Table 2.5: The domains used in different VdTMoCA assessment tools and outcome measures

Tool	Activity Participation Outcome Measure (APOM)[21]	Creative Participation Assessment tool (CPA)[19]	Functional Levels Outcome Measure (FLOM)[20]	Occupational Therapy Creative Ability Programme (OTCAP)[5]
Domains	• Process skills • Communication/ interaction skills • Life skills • Role performance • Balanced lifestyle • Motivation • Self-esteem • Affect	• Action • Volition • Handle tools and materials • Relate to people • Handle situations • Task concept • Product • Assistance/ supervision required • Behaviour • Norm awareness • Anxiety and emotional responses • Initiative and effort	• Mental illness • Orientation • Self-care • Appearance • Continence • Social behaviour • Activity participation • Domestic activity • Responsibility • Employment potential	• Motivation • Action • Quality of product • Relational contact with materials and objects • Relational contact with people • Relational contact with situations • Control of anxiety • Ability to show initiative • Ability to make an effort

In the determination of a patient's level of motivation and action, de Witt[53] emphasises the importance of using performance areas, namely personal management, social ability, work ability and constructive use of free time. Performance areas are also included in the APOM under the domains "Communication and interaction", "Life skills", "Role performance" and "Balanced lifestyle",[29] as well as in the FLOM under the domains "Self-care", "Social behaviour", "Activity participation" and "Employment potential".[53]

2.5.2 Psychometric properties of the tools based on motivation and action

Casteleijn conducted research to determine the psychometric properties of the APOM,[29] CPA[51] and FLOM.[52] An explanation of the psychometric properties can be found below.

2.5.2.1 Activity Participation Outcome Measure

During Casteleijn's research on the psychometric properties of the APOM, it was found that the content validity of the measure was of statistically significant value.[29] This was supported by the results of the content validity index calculations and the judgements of the individual item descriptors performed by experts on the subject matter. Despite the naivety of the data set at the time when the construct validity was determined, the measure showed construct validity of statistically significant value. The inter-rater as well as intra-rater reliability was also found to be significant, with the intra-rater reliability being dependent on the therapists understanding of the underlying theoretical concepts, their clinical experience and the characteristics of each level.[29]

2.5.2.2 Creative Participation Assessment

Casteleijn found that the CPA showed inter-rater reliability of significant statistical value.[51] This was however dependent on the therapists understanding of the underlying theoretical concepts of the VdTMoCA as well as their understanding of the characteristics of each level of Creative Ability. Casteleijn also reported that the CPA showed adequate content and construct validity.[51]

2.5.2.3 Functional Levels Outcome Measure

Casteleijn investigated the psychometric properties of the FLOM and, together with the Rasch analysis, concluded that the FLOM has excellent internal construct validity with good item functioning. Casteleijn also found that the FLOM shows good inter-rater reliability provided that the therapist is familiar with the characteristics of all the levels of Creative Ability.[52]

2.5.2.4 Confirmation of the levels of Creative Ability

Health care professionals across the world are responsible for measuring the effectiveness of their services, thereby providing information regarding the noticeable quality and value of treatment. In order to be able to report on these, professionals require valid and reliable measurement instruments.[1] Most occupational therapy assessment tools are on an ordinal scale which inhibits the interpretation of data due to unequal distances between points.[1] This type of scale therefore cannot be used as an outcome measure. Data on a level three, namely an interval scale, can be used as a measure of outcome as the intervals between each category are equal.[1]

In Casteleijn's study to confirm the levels of Creative Ability, Casteleijn used the Rasch measurement model to assess the hierarchical nature of the levels in each of the APOM, CPA and FLOM. This model converts ordinal measures into interval/linear measures.[1,11-15] Casteleijn's study concluded that the levels of Creative Ability fit Rasch's model well and therefore the data could be successfully converted into interval measures. It can therefore be concluded that the levels of Creative Ability can be used as a reliable outcome measure in occupational therapy.[1,11-15]

2.6 Models currently used in the treatment of patients with ABI's

There are a number of scales and models currently used in practice during the treatment of patients following an ABI that assist medical team members and families with classifying the patient on a specific level for prognostic reasons and for the purpose of guiding treatment. These models have been developed according to the recovery of patients following an ABI and are commonly used models in the field of neurology.

2.6.1 Disorders of Consciousness

Disorders of Consciousness (DOC)[54] can be diagnosed due to focal brain injuries that result in widespread functional impairments. They are categorised largely on observable behaviour and the behaviour's inferred relationship with consciousness. The disorders of consciousness exist on a continuum, with patients transitioning sequentially though each state. There are four disorders of consciousness, namely coma, vegetative state, minimally conscious state and post-traumatic confusional

state. There are well established guidelines on the diagnosis of each of these states.[54]

2.6.2 The Rancho Los Amigos Scale

The Rancho Los Amigos Scale[55] was developed by a rehabilitation hospital that specialises in brain injuries. The scale is used to rate how patients with TBI's recover following injury. There are ten levels of recovery, which exist on a continuum. The scale is used only as a guide because patients recover at different rates and therefore may demonstrate aspects of more than one level at a time.[55] The levels of the Rancho Los Amigos Scale can be found in Table 2.6.

Table 2.6: Rancho Los Amigos Scale

Level	Description
Level 1	No response
Level 2	Generalised response
Level 3	Localised response
Level 4	Confused - agitated
Level 5	Confused – inappropriate – non agitated
Level 6	Confused – appropriate
Level 7	Automatic – appropriate
Level 8	Purposeful – appropriate (stand-by assistance)
Level 9	Purposeful – appropriate (stand by assistance when requested)
Level 10	Purposeful – appropriate (modified independence)

The Rancho Los Amigos Scale is taught at South African universities to undergraduate occupational therapy students and is therefore a well-known scale amongst occupational therapists in South Africa. For this reason, the level according to the Rancho Los Amigos Scale is included under the motivation domain in the outcome measure that was developed by this study, to assist therapists in practically identifying behaviours in their patients while using the measure.

2.6.3 The Glasgow Coma Scale

The Glasgow Coma Scale (GCS) is reportedly the most common scale used to describe a patient's level of consciousness following a traumatic brain injury.[56] The scale assists health professionals in determining the severity of an ABI. The scale is reliable, simple and correlates well with the outcome of patients following an ABI.[56] There are three sections that need to be scored, as seen in Table 2.7 below.

Table 2.7: Glasgow Coma Scale

Eye Opening	
4	Spontaneous
3	To sound
2	To pressure
1	None
Verbal Response	
5	Orientated
4	Confused
3	Words, but not coherent
2	Sounds, but no words
1	None
Motor Response	
6	Obeys commands
5	Localising
4	Normal flexion
3	Abnormal flexion
2	Extension
1	None

Health care professionals are required to score the best response to each of the items seen in Table 2.7 and the total of these is the final GCS score. According to the GCS, brain injuries can be classified as[56]:

- Severe: GCS of 8 or less
- Moderate: GCS of between 9 and 12
- Mild: GCS of between 13 and 15

The GCS is commonly used in hospitals in South Africa and therefore widely understood amongst rehabilitation staff, nursing staff and doctors. For this reason the GCS that corresponds with each level of Creative Ability for patients following an ABI, is included in the outcome measure that was developed in this study.

2.6.4 Maslow's Hierarchy of Needs

Maslow[57] stated that people are motivated to achieve specific needs and that, at different phases, some needs take precedence over others. The most basic human need is survival and this will therefore take precedence over any other need. According to Maslow,[58] a person cannot focus their attention on a higher need unless the previous need has been met. He developed a hierarchy of needs which can be correlated with the different levels of Creative Ability according to their level of motivation.[57] The hierarchy of needs can be seen in Figure 2.1 below.

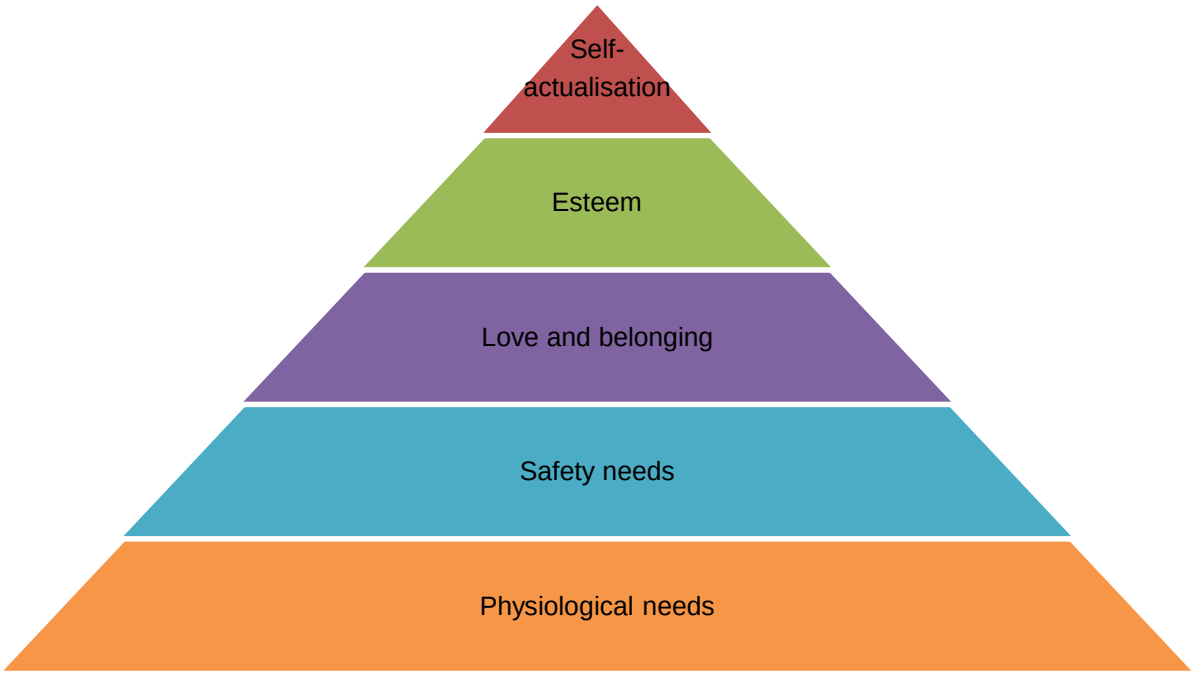

Figure 2.1: Maslow's Hierarchy of Needs

2.7 Concluding remarks

This chapter emphasised the lack of academic literature into the use of the VdTMoCA in the field of neurological occupational therapy. It outlined the importance of motivation in the assessment of patients following an ABI, and the importance of the inclusion of occupational performance areas in an outcome measure. Despite much research being done in the psychiatric field of occupational therapy, it is evident that further research needs to be conducted to develop tools for use in neurology as the tools already developed, namely the APOM, CPA, FLOM and OTCAP, do not incorporate neurology-specific terminology and clinical presentations.

Literature indicates that the psychometric properties of the VdTMoCA tools and measures are of statistically significant value, with sound evidence indicating that the levels of Creative Ability do exist.[9] The Model has also been converted to an interval/linear scale, which confirms that it can be used as an outcome measure in clinical practice.[1]

The development of such an outcome measure in neurology would allow therapists to conduct client-based assessments and provide level-directed therapy to patients by delivering the “just right challenge” which prompts progression to higher levels of functioning. The outcome measure would also provide therapists with a means to measure the effect of therapy and provide health care professionals, families and employers with valuable knowledge regarding the level of independence of patients prior to discharge.

The following chapter will focus on the research design and methodology used during the study in order to answer the research question and reach the research objectives.

CHAPTER 3 :
RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

In this chapter the design and methodology used in the first objective of this study will be described. Research design and methodology is not specifically discussed here for the second objective, as it was an academic and theoretical process rather than research with design and methodology. Literature is revised throughout this chapter in order to clarify the choice of design and methodology. Firstly, an overview of the research design is given, followed by the methodology. This includes defining the setting/context, outlining the research population and sample. An in-depth discussion regarding the data gathering method is then provided. Various methods of data analysis are then discussed, with a conclusion and in-depth description of the method chosen. Lastly, the ethical consideration used in this study is discussed.

3.2 Research design

Vickie and Clinton[33] state that many times research is given qualitative research designs (such as grounded theory, phenomenological etc.), without fully meeting the requirements set out by these designs. Mason[59] states that despite the difference in purpose and development of qualitative design when compared to a quantitative design, it is still of utmost importance to develop and define this design. To think qualitatively means rejecting the thinking that a research design is a single document which stands as an advance blueprint for the entire research. It is also to reject the idea that the decision making surrounding research design is a once off process. Qualitative research is characteristically exploratory, flexible and fluid in nature. It is also context-sensitive and data-driven. Given the above mentioned qualities of qualitative research, it is therefore impossible to write a whole advance blueprint when developing qualitative research design.[59]

The process of decision making regarding the research design in qualitative studies is ongoing and grounded in practice and context.[59] Despite the impossibility of designing an entire advance blueprint, it is still essential to develop a research design at the start of the research process, although this contemplation regarding design

and strategy should not stop there but rather be an ongoing process throughout the research study.[59]

This study contained elements of phenomenology, in that the descriptions of each domain were obtained through the life world and experiences of therapists. This study did not fully fit the description of phenomenology as there was a pre-given framework, as well as a specific model (the VdTMoCA) according to which the information should pertain.[32]

Therefore, the proposed research study followed a qualitative descriptive design, as straightforward description of phenomena was required, with no pre-selection of variables, no manipulation of variables as well as limited commitment to a specific theoretical view of a phenomenon (i.e. the VdTMoCA).[60]

3.3 Study population and Sample

3.3.1 Setting/Context

The study and developed outcome measure is applicable to the adult neurological occupational therapy context of South Africa.

The study took place at various locations in the Gauteng Province, in order to accommodate therapists working in different cities and areas. The locations were also chosen for their suitability for the size and purpose of the specific group.

3.3.2 Participants

3.3.2.1 Research Population

Polit and Beck[61] define a research population as “the entire set of individuals or objects having some common characteristic”. They continue to define the difference between a *target population* and an *accessible population*. According to Polit and Beck,[61] a target population is the entire group/population about which the researcher would like to generalise. On the other hand, an accessible population is the group/population that meets the defined criteria and those that are accessible and able to be used as subjects of a study.[61]

The target population for this study was defined as occupational therapists working within the neurological rehabilitation setting (acute as well as chronic), including

those in academics. This population covers but is not limited to occupational therapists working within the neurological rehabilitation setting in private practices, government institutes, non-profit organisations as well as in academics (at universities).

The lack of a South African database for occupational therapists working in neurology made it impossible for the researcher to define the parameters of the population. Despite all occupational therapists needing to be registered with the Health Professions Council of South Africa (HPCSA), this database does not indicate the therapist's field of practice or years of experience.

The Occupational Therapy Association of South Africa (OTASA) comprises a more detailed list of therapists and their specialities, although it is not compulsory for therapists to belong to this organisation and therefore does not provide a detailed database for defining the parameters of the study population. This issue is further complicated by the fact that occupational therapists are not required to formally specialise in the field of neurology in order to work in the field.

3.3.2.2 Research Sample

Polit and Beck[61] define sampling as an action where part of a population is identified to represent the entire population.

The researcher adopted a purposive sampling method of convenience,[32] as all occupational therapists that fit the inclusion criteria were invited to participate. Polit and Beck[61] report that purposive sampling is a method that can be used by a researcher in order to choose certain members of a target population for a specific, defined reason. For this research, participants were chosen to represent their field of expertise, as well as for their in-depth knowledge and experience related to the topic under study.

The first objective of this study entailed the selection of occupational therapists working in the field of neurological rehabilitation that were able to provide informative data regarding domain descriptors for an outcome measure. Neurological rehabilitation settings in the Gauteng Province were judged as a fair representation of the population of neurological-based occupational therapists and chosen for

convenience reasons and therefore all included in the sample. Neurological rehabilitation settings were identified by use of the internet as well as consulting with clinical therapists for advice regarding hospitals and practices that treat patients who have suffered an ABI. A list of all the appropriate hospitals and practices was drawn up, with contact details and email addresses obtained by word of mouth and researching on the internet. For privacy and confidentiality purposes, this list is not included in this thesis.

Occupational therapists with at least two years of experience in neurology were defined as experts in the field of neurology and therefore eligible for inclusion. This experience included working for at least two consecutive years in the field of adult neurology, with essential experience in treating patients following an acquired brain injury. The study also required that the occupational therapists be trained in the use of VdTMoCA at an undergraduate or postgraduate level (even if this training was only psychiatric based). It was also required that the participants be conversant in English as this is a universal language and most commonly the language of education. The reason for this requirement was to ensure that the groups were able to run smoothly, without interruptions for translation during discussions. The use of one common language also ensured that the verbatim transcription of the focus groups was focused and the information did not lose its meaning in the translation process.

Once the above mentioned list was developed with the contact details of private, government and academic occupational therapists, the potential participants were invited by the researcher to participate in the study. Emails containing the participant information leaflet and informed consent (refer to Annexure A) were sent out with choices of dates and venues. Therapists were requested to suggest other therapists within Gauteng as well as to invite additional potential participants within their place of work. Follow up emails were sent by the researcher to remind potential participants to respond to the invitation. The use of a demographics form attached to the participant information leaflet and informed consent ensured that all participants fell within the above mentioned criteria (see Annexure B).

The researcher applied for four continuing professional development (CPD) points, to allocate to participants who partook in the research. This was deemed an appropriate

number of points as therapists gained invaluable in-depth knowledge about the VdTMoCA by discussing the Model with other experienced therapists.

3.3.2.3 Inclusion criteria

The participant's job, knowledge, availability as well as experience are all commonly used criteria while selecting participants to be included in a study.[32] These were all considered while defining the inclusion criteria for the participants of this research. It was essential that the participants have at least two years of experience in neurological rehabilitation (and it be current) to ensure the evidence obtained is most recent. Two years was defined as enough to provide focused, experienced based evidence, while not severely limiting the number of eligible therapists.

The inclusion criteria were as follows:

- Occupational therapists registered with the Health Professions Council of South Africa (HPCSA)
- At least two years of experience as an occupational therapist working in neurological rehabilitation (this can include the therapist's community service year)
- Trained in the use of the VdTMoCA at an undergraduate or postgraduate level (even if this training was only psychiatric based)
- Conversant in English
- Currently working in a private practice, government institute, university or non-government organisation, in Gauteng, South Africa

3.4 Data gathering method

3.4.1 Demographic questionnaire

The demographic questionnaire (Annexure B) was developed for potential participants of this study. The researcher studied previously developed demographic questionnaires in order to ensure that all relevant information was included in the questionnaire used in this study. A piloting of the questionnaire was performed with one lay-person and an occupational therapist who did not participate in this study, so that the researcher could establish if the questions could be understood by all participants.

Upon reviewing literature,[62-63] it was found that the following is essential for the demographic questionnaire for this study:

- Place of undergraduate study (as this provides the researcher with valuable information regarding the degree of undergraduate exposure to the VdTMoCA)
- Years of experience in neurology
- Direct exposure to the VdTMoCA (at an undergraduate or postgraduate level)
- Neurological specific post graduate courses attended

It was important that the researcher not include any personal, or work information in the demographic questionnaire, as the participants consented to participate in their personal capacity and in no way be associated with their place of work (private, government etc.).

An electronic fill-in form was designed and developed as well as the possibility of a hard copy. Both of these options were piloted with the pilot participants to ensure that the questions were understandable and both the electronic copy and the hard copy were easy to fill in. No concerns or possible changes were found during the piloting of the questionnaire.

3.4.2 Focus groups

Focus groups have been found to be an acknowledged means of obtaining information.[32] The method was established in the early 1960's and they have been extensively used in qualitative research since the 1990's. Focus groups develop a process of comparing and sharing information among the participants. It allow researchers to create a well-defined purpose, which give participants the opportunity to produce large amounts of concentrated data.[29,32] Focus groups are conducted as an open but focused conversation between participants, typically in a series in order to generate confirmatory data and to ensure data saturation.[29]

There are many advantages of focus groups as a method of gathering data, including the saving of time and money compared to individual interviews. They also provide an opportunity to ask for clarification and allow the researcher to obtain detailed

information about group and personal feelings, opinions, perceptions and experience.[29,64] The group process allows participants to expand on the responses given by others which consequently increases the amount of rich and comprehensive data obtained from such groups.[29]

The disadvantage of focus groups include; difficulty analysing qualitative data, altered generalisability of the data due to the sample of convenience and disagreements or irrelevant discussions that may distract from the original purpose of the focus group.[29,64]

Focus groups require a moderator to be present throughout the group. This moderator facilitates the discussion of a specific topic related to the purpose of the group and therefore does not actively participate in the discussion. Their role is to encourage interaction amongst participants as well as to allow the discussion to flow naturally. The moderator is however required to ensure that the discussion stays focused and relevant to the purpose of the group and provide cues to promote further discussion. For this reason, it is important that the moderator is knowledgeable in the field of study and confident in the facilitation of the group process. It is also important that the moderator listen openly and intensely throughout the group. While interacting with participants to facilitate discussion and probe for deeper meaning, the moderator needs to remain non-judgemental and non-authoritarian.[29]

In all of the focus groups held for this study, the researcher was the moderator. Refer to Annexure C for the Vignette of the researcher. Research and consultation with professionals was also conducted prior to the focus groups to ensure that the researcher was knowledgeable on the group process and on the conducting of focus groups.

An interview guideline is usually prepared prior to the start of a focus group, in order to guide the direction of the discussion (see Annexure D for a guideline of the questions that were used during the focus groups). This interview guideline was given to an occupational therapy expert in the field of neurology, with exposure to the VdTMoCA, who did not participate in a focus group, to review to ensure applicability of the guidelines and questions. No changes were made by the expert.

3.4.2.1 Research procedure

There is no rule of thumb regarding the number of focus groups that should be held, although Krueger[32] suggests that four group meetings, with re-evaluation after the third is sufficient. The largest amount of new information is usually generated in the first two meetings, with repetition and saturation noted thereafter. For the purpose of this research, the researcher continued to conduct focus groups with re-evaluation after each, until data saturation was reached.[32] A total of four groups were held, with 19 participants in total. These four groups were held over a period of four months between May 2018 and August 2018.

According to Greef,[32] focus groups usually include six to ten participants per group, although also explicitly states that this can be more or less (between three to six participants), depending on the needs of the group. Greef also recommends that researchers should over-recruit by 20% to compensate for participants who do not arrive for the focus groups.[32] For the purpose of this study, it was decided that groups would have between four and eight participants to ensure that discussion was possible. For this reason, a group initially arranged for April 2018 had to be postponed due to only three participants indicating that they could attend. The number of participants per group varied greatly due to date, time and location.

The researcher limited homogeneity of participants as far as possible, to increase the richness of data received through the sharing of diverse information during the focus groups. This was ensured through the mixing of areas in the focus groups, in order to make sure that one focus group was not held only with therapists from the same hospital. Although this was the intention, it was not possible due to difficulties in recruiting participants. One of the focus groups conducted, contained only therapists from the same hospital. The researcher ensured that homogeneity was still limited in these groups by assessing the demographics forms and ensuring that the participants varied in terms of years of experience and place of undergraduate study.

The focus groups were held at various locations in Pretoria and Johannesburg that were suitable and convenient for the participants, as well as suitable for the conducting of a focus group. Tea, water and snacks were provided. All discussions

were voice recorded as stipulated in the informed consent for verbatim transcription purposes.

The researcher ensured that all four focus groups followed the same structure, with the same cueing from the moderator/researcher in order to ensure consistency.

The predetermined structure followed during the focus group can be found below:

a) Opening/welcoming
b) Discussion of the rules
c) Overview of the levels of Creative Ability
d) Overview of the domains
e) Overview of the performance areas
f) Introductory question per level
g) Introduction of each domain
h) Closing of each domain
i) Closing of each level
j) Summary and closing

Steps six through nine were repeated for each of the six levels of Creative Ability discussed in the groups.

Each participant was encouraged to share their views throughout the focus group. A PowerPoint presentation was used in order to guide the participants through the different domains, performance areas and levels of Creative Ability (refer to Annexure E for an example of this presentation). The PowerPoint presentation included essential information from the VdTMoCA in order to recap the different levels, as well as to ensure that the discussion remained in line with the Model and its essential features. During the discussions, the moderator/researcher recorded the information given by the participants on the PowerPoint presentation and therefore this served as field notes during the groups as well as a guide for the participants.

Greef[32] recommends that focus groups should not exceed 120 minutes in length, although this was not always possible, with some of the groups continuing for up to 180 minutes.

3.5 Data organisation, analysis and interpretation

3.5.1 Demographic questionnaire

Demographic questionnaires were obtained prior to the focus groups. This was to ensure that all participants met the inclusion criteria. The raw data obtained from the questionnaires was captured into a Microsoft Excel spreadsheet. Graphs were drawn to illustrate the demographics of the sample and can be found in Chapter 4.

3.5.2 Focus groups

There are a number of different methods of qualitative data analysis available to researchers. For the analysis of focus groups, it is recommended that a pattern-based qualitative analytic method be used. These include interpretive phenomenological analysis (IPA), grounded theory and thematic analysis, to name a few of the most popular methods.[65] It was therefore essential that the researcher conduct a review of literature in order to determine the most appropriate analytic method to be used for the analysis of the focus groups. This review can be found below.

Grounded theory was designed for the development of new, contextualised theories. The approach allows researchers' to move from data to theory without relying on analytic constructs, categories or variables from pre-existing theories.[66] As an analytic method, grounded theory provides researchers with guidelines on ways of identifying categories, ways to make links between categories and ways to establish relationships between them. Grounded theory as a *theory* is unlike other methods of research in that it combines data collection and analysis. The researcher is expected to analyse data as it is captured and change the direction of the research or the research question as needed. This therefore indicates that the research cannot follow a specific predetermined framework or model and was therefore not an appropriate analytic method for this study.[66]

Interpretive phenomenological analysis (IPA) is a method of analysis aimed at exploring in detail how participants make sense of their social and personal world. The approach is phenomenological, involving a detailed examination of the participant's life-world. The analysis of data attempts to explore personal experience, instead of attempting to produce an objective statement of the object or event. Once

IPA has been chosen as the analytic method, it is important to note that recording of the interviews or groups is vital. This allows for verbatim transcription and the identification of themes and codes. Phenomenology states that there should be no predetermined framework or model, as these items are obtained during the analysis of the transcribed data. This approach was therefore not suited for use in the this study, due to the presence of a predetermined framework and model (VdTMoCA).[67]

Thematic analysis (TA) is not tied to a particular theoretical framework. TA purely provides a method rather than a methodology for qualitative research. It provides researchers with a six step process of data analysis. There are many different versions of TA, with the method developed by Braun and Clarke[65] being the most popular, straightforward method described.[67] Due to the approach merely providing a method, not tied to a theoretical framework, this approach could be considered for use in this study.

Table 3.1 below provides a comparison of qualitative research analysis methods to further justify the choice of data analysis method.

Table 3.1: Comparison of methods of data analysis

	Qualitative	Descriptive	Explorative	Commitment to a specific approach	Method or methodology	Flexible	Specific guidelines / steps given
Interpretive phenomenology approach	Yes	Yes	Yes	Yes – Phenomenological	Methodology	No	No
Grounded theory	Yes	Yes	Yes	Yes – grounded theory	Methodology	No	No
Thematic analysis	Yes	Yes	Yes	No	Method	Yes	Yes

As seen above, thematic analysis is the most suitable method of data analysis for the data obtained from the focus groups of this study. TA was first developed by Holton in the 1970's. Since its development, TA has been extensively used for analysing qualitative data despite a lack of discussion and research into this method of analysis. In 2006, Braun and Clarke[65] developed a systematic approach to TA, which is currently being used in many qualitative studies. For Braun and Clarke,[65] TA involves more than reporting on what the data has found; they indicate that TA data tells an interpretive story regarding the data, in relation to the research question.[65]

TA has a unique flexibility and the potential to be used in a variety of ways. The advantages of TA are as follows[65]:

- TA can be used to answer a wide number of research questions (about practices and behaviours, experiences or perspectives, influencing factors etc.).
- TA can be used with almost any kind of qualitative data. This can be data obtained through a researcher interacting with participants (focus groups or interviews), data obtained by participants writing responses to questions (qualitative surveys) and data obtained through secondary sources of data (magazines).
- TA can be used for smaller and larger datasets.
- TA can also be used to analyse and theorise data – it is not tied to a particular epistemological or theoretical framework.
- TA is used to summarise and provide a rich description of a set of data. This provides the researcher with key themes and patterns of meaning at the semantic level.
- TA has clear guidelines for conducting analysis.

Braun and Clarke's[65] approach to TA involves a six-step recursive process. The data in this study was analysed using these six steps. An overview of the steps is given in Figure 3.1 below, with a more comprehensive description of each step provided below.[65]

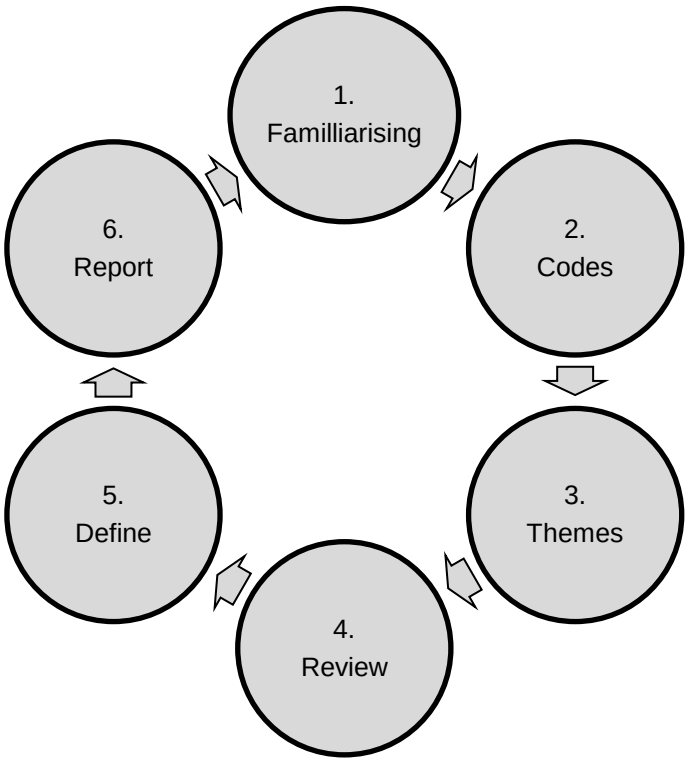

Figure 3.1: The six steps of thematic analysis

3.5.2.1 Step one: Familiarising oneself with the data and identifying items of potential interest

This step is common to most forms of qualitative data analysis. According to Braun and Clarke, during this step, the researcher is required to immerse themselves in the data by reading and re-reading every bit of data available.[16] The researcher transcribed the data verbatim from voice recordings taken in each focus group. This was the initial step of immersing herself in the dataset.[68] Thereafter, the researcher re-read all the transcription while re-listening to the recordings to ensure accuracy of transcriptions as well as further immersion in the data. During the whole process, the researcher started to identify and record in a spreadsheet, potentially interesting features mentioned in each group for each level of Creative Ability. The transcriptions were re-read with the PowerPoint slides available for comparison and summary.[68]

3.5.2.2 Step two: Generating initial codes

The researcher was concerned with addressing a specific research question as mentioned in Chapter 1 and therefore analysed the data with this in mind.[65] For this reason, a theoretical, deductive thematic analysis method was adopted, rather than an inductive one. The researcher therefore coded each level of Creative Ability and domain according to the cues given in the Model.[68] The researcher therefore did not code line-by-line, but rather each section of data that was relevant to the research question. Open coding was used, where no pre-set codes were developed, but the codes were rather developed and modified as the coding process proceeded. Codes were added into tables and along the margins of the transcriptions. Re-coding was also performed by the researcher, by coding the data again from a clean slate in order to compare the codes identified. An example of the format used to code the transcriptions can be found in Table 3.2 below.

Table 3.2: An example of coding used in this research

Self-Differentiation		
Participant	**Transcription**	**Codes**
Researcher	So Self-Differentiation would be aimed at establishing and maintain self-awareness as a separate entity from the environment, objects and people. There are the 2 actions within Self-Differentiation – the one being destructive action and the other being incidentally constructive action. So with destructive action, it is the most primitive interaction that a person can have with the world. Destructive action aims to define their body boundaries and practice the basic skills. And the incidentally constructive action is the unplanned, unintentional constructive action that results by chance, so it is not a planned process, in an immediately recognisable end product. So motivation we have egocentric, to differentiate themselves from others. And then action, how would a neuro patient on Self-Differentiation look?	Not coded
3	"Like pulling on tubes, NG's [nasogastric tubes] and stuff"	Pulling at tubes
5	Ja	Pulling at tubes
1	Reacting to irritants or reacting to	Reactive
4	There might be a restraint because of that kind of behaviour, attempting to either pull out the NG or catheter	Restrained, pulling at tubes

3.5.2.3 Step three: Searching for themes

A theme is a pattern that captures something interesting about the research question. According to Braun and Clarke,[65] there is no specific rule about what makes a theme, but it is rather characterised by its specific significance to the research.[66] While searching for themes, analysis shifts to a wider focus. Despite the step being coined "searching", it should be noted that this step is an active one - it involves looking through the codes developed for broader patterns of meaning. This can be done in two ways; by promoting a particularly large and complex code to a theme or by combining similar codes together to form a theme.[68] A good theme can be defined as being standalone and distinctive, although all themes should work together to form a whole (answering the research question). The end of this phase is characterised by having a set of candidate themes, a sense of relationship between them and the collation of coded data relevant to each theme.[68] An extract of the format used while searching for themes can be found below in Table 3.3.

Table 3.3: An example of the format used while searching for themes

	Focus group 1	Focus group 2
Self-Differentiation: **Action**	**Theme:** Destructive **Codes:** • Pulling at tubes • Restrained • Unaware • Not participative • Reactive	**Theme:** Destructive **Codes:** • Pulling, pushing • Avoidance behaviours

3.5.2.4 Step four: Reviewing potential themes

The first level of this step is to ensure that the themes make sense in relation to the coded data (are the most important features of the coded data captured?).[68] During this level, the researcher reviewed, modified and developed the preliminary themes that were identified in step three. The researcher gathered together all data that was relevant to each theme and colour-coded all the data per theme. This was done by re-reading all the data associated with each theme and deciding whether or not the data supports the theme.

The second level of step four is to ensure that the themes make sense in relation to the whole set of data. This was done by ensuring that the themes work both within a single focus group as well as across all the focus groups.[68]

The following questions were asked throughout the review process[68]:

- Are the themes supported by the data?
- Is there too much information in one theme?
- Are the themes logical? (Do they make sense?)
- Are there sub-themes?
- Is there information within the codes and data that should rather be themes?
- Are themes that overlap really separate themes?

The researcher reviewed the themes and data captured to ensure that the research question was covered, as well as ensuring that the data was represented as a whole. To do this, the researcher took the themes and codes for all four focus groups and combined to form common themes per domain for each level of Creative Ability, with substantiating codes. These substantiating codes are the most relevant codes attached to the particular theme, that provide added meaning to the theme for easier recognition of that attribute within a patient. The researcher ensured that all codes and data were included under the theme. An example of a reviewed table of themes can be found in Table 3.4 below.

Table 3.4: An example of a reviewed table of themes

	Reviewed/combined themes
Self-Differentiation **Action**	**Theme:** Destructive **Substantiating codes:** • Pulling at tubes • Restrained • Unaware • Not participative • Reactive • Avoidance behaviours

3.5.2.5 Step five: Defining and naming themes

This is the most substantive stage, where the interpretive analytic work is done.[66] During this stage; the researcher produced detailed and complex definitions of each theme and related themes to each other.

The researcher selected the data extracts that were used in the final report. This data clearly addresses all aspects of the research question (these data extracts can be found in Chapter 4). The researcher also gave finalised names to all the themes. It was important that the names which the researcher chose were informative and engaging to ensure that therapists making use of the measure are able to easily understand the wording and identify such behaviour in patients.[68] To ensure that these themes are carried across effectively, and to provide added meaning to the themes, substantiating codes were included in this phase. These substantiating codes are the most relevant codes attached to a particular theme to allow for easier recognition of that attribute in a patient. These substantiating codes are often examples of what a patient following an ABI would look like on that level and therefore also provide further neurology-specific terms to the outcome measure.

Figure 3.2 gives an outline of the thematic map used during step five of TA. After data analysis, the finalised themes were placed under each heading shown in the figure.

Table 3.5 provides a visual representation of the finalised themes and substantiating codes. The theme can be seen as the heading, while the substantiating codes are the bullets below the main theme. The finalised names will be discussed in more detail in Chapter 4.

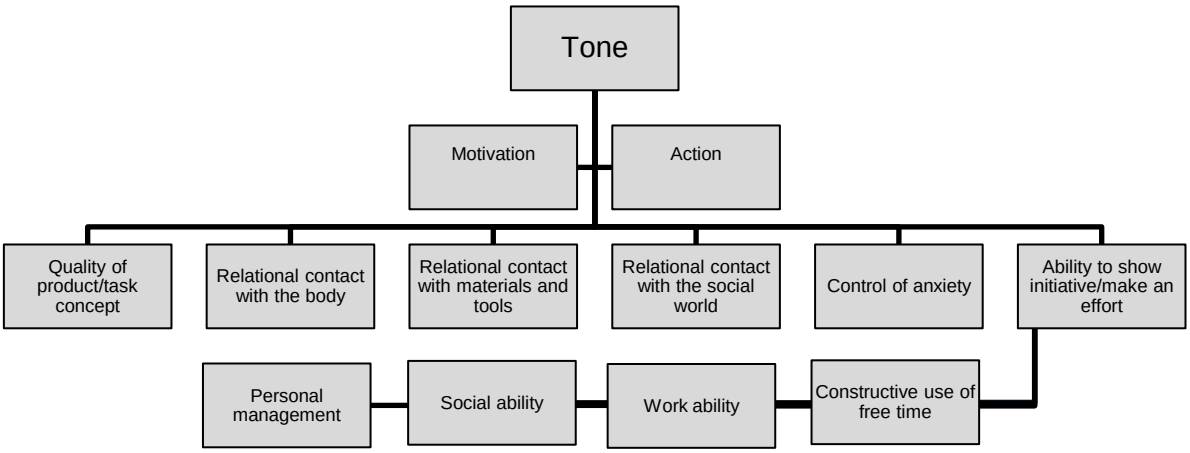

Figure 3.2: Thematic map of the level Tone

Table 3.5: An extract from the finalised themes and substantiating codes used in step five

SELF-DIFFERENTIATION		
Motivation	Egocentric • Instant gratification • Based on a personal, immediate need	To differentiate self • Pulling tubes Emergence of participation • Unplanned

3.5.2.6 Step six: Producing the report

The final step of the TA process is the writing of a report. This is an integral part of any study and generally the main reason for the use of TA. It should be noted that, as with all other qualitative analytic approaches, writing is an integral aspect of the analytic process. This means that by the time this step is reached, the report is usually close to being fully drafted.[68]

During this step the researcher, for the last time, refined the analysis of the data through the incorporation of literature. The themes and codes derived during the TA process were sent to an independent coder (an expert in neurological occupational therapy and the VdTMoCA). The independent coder re-coded the transcribed data to increase credibility as well as ensure that the themes and codes were a representation of the data as a whole. The researcher and independent coder then translated these finalised themes into domain descriptors to be used in the outcome measure through the review of literature available on patients with ABI's as well as the VdTMoCA. Various available VdTMoCA outcome measures were analysed (refer to Chapter 2). These measures were used as a base for the format of the measure developed in this study. For the framework of the outcome measure developed in this study, refer to Annexure F.

3.5.3 Trustworthiness of data

Qualitative research comprises of the subjective meanings, experiences and perceptions of participants, combined with the subjective interpretation of this data by the researcher. This could compromise data, deeming it invalid or unreliable. In qualitative terms, these factors could deem the data neither plausible nor trustworthy.[29] Four strategies to establish trustworthiness were suggested by Krefting[69]: credibility (this being internal validity in quantitative research terms), transferability (being external validity), dependability (which is reliability) and confirmability (objectivity).

The researcher applied these strategies during all the phases of this study (research design, data collection and interpretation). The application of these four strategies during the course of this study, to ensure true reflection and presentation of the data, is explained below.

3.5.3.1 Credibility

Credibility is one of the most important factors in establishing trustworthiness.[34] Krefting[69] reminds researchers that the true value of the data and research is subject-oriented. Despite this, it is the researcher's responsibility to present the data truthfully and accurately.[29,69] The researcher used the methods explained below to ascertain the presentation of truth during data collection and analysis.

The term “prolonged engagement” was introduced by Lincoln and Guba.[70] Prolonged engagement refers to the researcher’s need to ensure intimate familiarity with the research setting, with the intention of uncovering hidden facts and rich data.[29,70] For this study, the researcher ensured prolonged engagement in the field of neurological occupational therapy. The researcher has actively worked in the field of neurological occupational therapy for three years and is therefore familiar with the research setting and information shared by the participants. As a result of this prolonged engagement by the researcher, the researcher was able to identify with the comments made by participants in the focus groups. Krefting[69] cautions against participants providing the socially desirable responses during focus groups, rather than relating to their own experience and knowledge. This was also overcome with the researcher’s prolonged engagement in the research setting. During the focus groups, questions occasionally had to be reworded in order to elicit the participants’ exact perceptions and experiences.[69] Prolonged engagement with the data was also ensured with the organisation of focus groups continuing until data saturation was reached.

The researcher’s influence on the results obtained from qualitative research must be acknowledged and accounted for. Reflexivity is seen as an effective way of revealing the researcher’s perceptions in the research process.[29] For this reason, a vignette about the researcher can be found in Annexure C. The researcher also had to ensure that accurate interpretation of the data occurred at all times and for this reason, reflection and review of the PowerPoint slides and recordings followed each focus group. This allowed the researcher to adapt methods within the focus groups and to ensure that the researcher was not leading the group in a subjective direction.

To prevent the misinterpretation of data, it is recommended that an independent coder review the transcribed data and derived themes and codes.[68] Following the final focus group, the researcher transcribed the data and used thematic analysis to develop codes and themes. The independent coder (who was an expert in the field of neurological occupational therapy as well as in the VdTMoCA) was then sent the transcribed data and the themes and codes derived by the researcher with the purpose of checking for accuracy and representation of the data set as a whole. During this process, the independent coder re-coded the data and then revised the

codes and themes derived by the researcher. A discussion between the researcher and independent coder then commenced to reach an agreement on the themes and codes that represent the data set as a whole.

An expert reviewer (an expert neurological occupational therapy with exposure to the VdTMoCA) was also used. The reviewer was sent the final outcome measure to analyse and determine if the descriptions were accurate.

The credibility (validity) of the outcome measure was further ensured through the review of literature. This literature included the VdTMoCA for mental health care users and children, as well as a number of scales currently well researched and used in patients following an ABI. These scales include the Rancho Los Amigos Scale,[55] the Glasgow Coma Scale,[56] the degrees of Consciousness[71] and Maslow's hierarchy of needs.[72] The researcher compared the data obtained from the focus groups for each level of Creative Ability to the above mentioned scales and models to ensure that the measure developed in this study is in line with well-researched literature and thereby increased the credibility (validity) of the tool.

3.5.3.2 Transferability

Transferability is not always an issue, as is the case if the research consists of a case study where the sole purpose of the investigation it to understand the dynamics of the case.[29] This is however not the case for this study, as the outcome measure developed had to be appropriate and relevant in all adult neurological occupational therapy practices.

The researcher ensured that the study findings are applicable to other contexts by ensuring that a representative sample was used. A comprehensive description of the sample was also provided so that the therapists interested in using the outcome measure developed in this study, could perform their own assessment on the transferability of the data to their own situation. The participants were able to give information-rich data on what information should be included in the outcome measure, as participants were deemed experts in the field of neurological occupational therapy and experienced in the VdTMoCA.

3.5.3.3 Dependability

Dependability is the consistency of the findings, as well as the repeatability of the study.[29] The dependability of the research was ensured through the use of the six steps in thematic analysis, the re-reading of the transcriptions as well as in the code-recode procedure. Further dependability was ensured through a dense description of the research methodology.

3.5.3.4 Confirmability

The term confirmability refers to the degree of bias in a study.[29] By nature, qualitative research requires the subjective involvement of the researcher throughout the entire research process. The researcher cannot take a neutral or objective stance. Lincoln and Guba[70] state that the neutrality of a qualitative study therefore shifts from the researcher, to the data set. The rigor lies in the data being neutral, meaning that the findings are solely those of the participants. Active involvement of the researcher is therefore clearly explained.[70]

The neutrality/confirmability of the research was emphasised by ensuring that researcher bias did not skew the interpretation of the participants' responses. A research trail was established, in which every step of the data analysis process was highlighted with the aim of ensuring that a rationale was provided for the relevant decisions made. A focus group guideline also ensured that participants' views were considered. The use of a PowerPoint presentation and summary of the groups' findings/decisions ensured that participants in each group agreed with the final data given for each level of Creative Ability per domain and performance area.

3.6 Ethical considerations

The research was guided by three fundamental ethical principles, as set out by Brink et al,[73] including: beneficence, respect for persons and justice.[29,73]

Beneficence refers to the researcher's duty to do no harm to the participants, but instead to promote good.[73] Although the research did not pose any threat to the participants physically, the researcher took caution to ensure that no emotional discomfort was experienced by any of the participants during the focus group. The participants will benefit from the study, as the study aims to provide neurological

occupational therapists with an outcome measure to be used during assessment, treatment and as a means of motivating the effect that occupational therapy has on recovery. The results of the study will provide neurological occupational therapists with a means to improving holistic, motivation-based patient assessment and treatment. The participants benefited from the focus groups through learning from other occupational therapists and were allocated the appropriate CPD points.

The research ensured that respect for all persons involved was maintained through the participants' right to self-determination, privacy, confidentiality and anonymity.[73] Consent to participate in the research was obtained from the participating occupational therapists. Participants were given all the relevant information prior to agreeing to participate and were given free will to decline inclusion in the study. The researcher undertook to ensure that all data was managed appropriately to ensure anonymity.

Lastly, the principle of justice was ensured by recognising that the participants have the right to fair selection and treatment.[73] The researcher ensured that the selection methods and inclusion criteria were followed in order to make sure that all participants were fairly selected.

The study has also received written approval from the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria. A copy of the approval letter can be made available if you wish to have a copy. Ethics Reference No: 37/2018 (see Annexure G for a copy of the approval letter).

Contact details:

Dr R Sommers

Deputy Chairperson: Faculty of Health Sciences Research Ethics Committee, University of Pretoria

Tel: 012 356 3084 or 012 356 3085

Email: deepeka.behari@up.ac.za or fhsethics@up.ac.za

3.7 Conclusion

This chapter provided an explanation of the research methodology used to develop an outcome measure based on motivation and action for occupational therapists in neurological rehabilitation. Through the use of focus groups, sufficient data was collected to develop this outcome measure. The study design, population, data collection, data analysis, trustworthiness and ethical considerations were explained. Chapter 4 will reveal the findings of this study.

CHAPTER 4 :
RESEARCH FINDINGS AND LITERATURE CONTROL

4.1 Introduction

Chapter 3 provided an in-depth description of the research methods, design and methodology applied to generate data. In this chapter, the research findings will be discussed in terms of the research objectives of this study, as seen in Chapter 1 and stated below.

The objectives of this research are:

- Objective 1: To develop domain descriptors for each of the first six levels of Creative Ability.
- Objective 2: To develop and design a user-friendly outcome measure using the information gathered in the first objective.

For objective one, the findings are reported as follows: firstly, a description of the demographic profile of the focus group participants is given; followed by the definition of neurology-specific domains and performance areas. This is followed by an overview of the analytical process. Finally, each theme generated from the focus group data with their substantiating codes, for each level of Creative Ability, is described. The findings are further triangulated by including a discussion for each level and brought together in a table indicating the progression through each level of Creative Ability. The themes and substantiating codes were converted into the domain descriptors to be included in the outcome measure, through the review of literature.

The chapter closes off with a discussion on the process of developing and designing the outcome measure format, as stipulated in objective two.

4.2 Demographic profile of focus group participants

All participants in this study were occupational therapists registered with the Health Professionals Council of South Africa (HPCSA), working in the Gauteng Province at the time of data collection. The participants' worked in either private or government hospitals or universities. To ensure confidentiality and anonymity was maintained; the

participants did not specify where they work. Four focus groups were held over a four month period, with a total of 19 participants. The profiles of the participants according to the demographic survey were as follows:

4.2.1 Participants' gender

All 19 participants in this study were female. Occupational therapy is known to be a predominantly female profession, which is represented in this data. In 2011, of the 3664 registered occupational therapists, 3501 of those were females, equating to 95.5% of the South African occupational therapy population.[74]

4.2.2 Years of experience

The participants' years of experience in neurological occupational therapy varied within groups as well as between groups, as depicted in Figure 4.1 below. The researcher rounded years of experience off to the nearest year (therapists with 3 years 2 months experience were indicated as having 3 years of experience and therapists with 2 years 8 months experience, were indicated as having 3 years of experience).

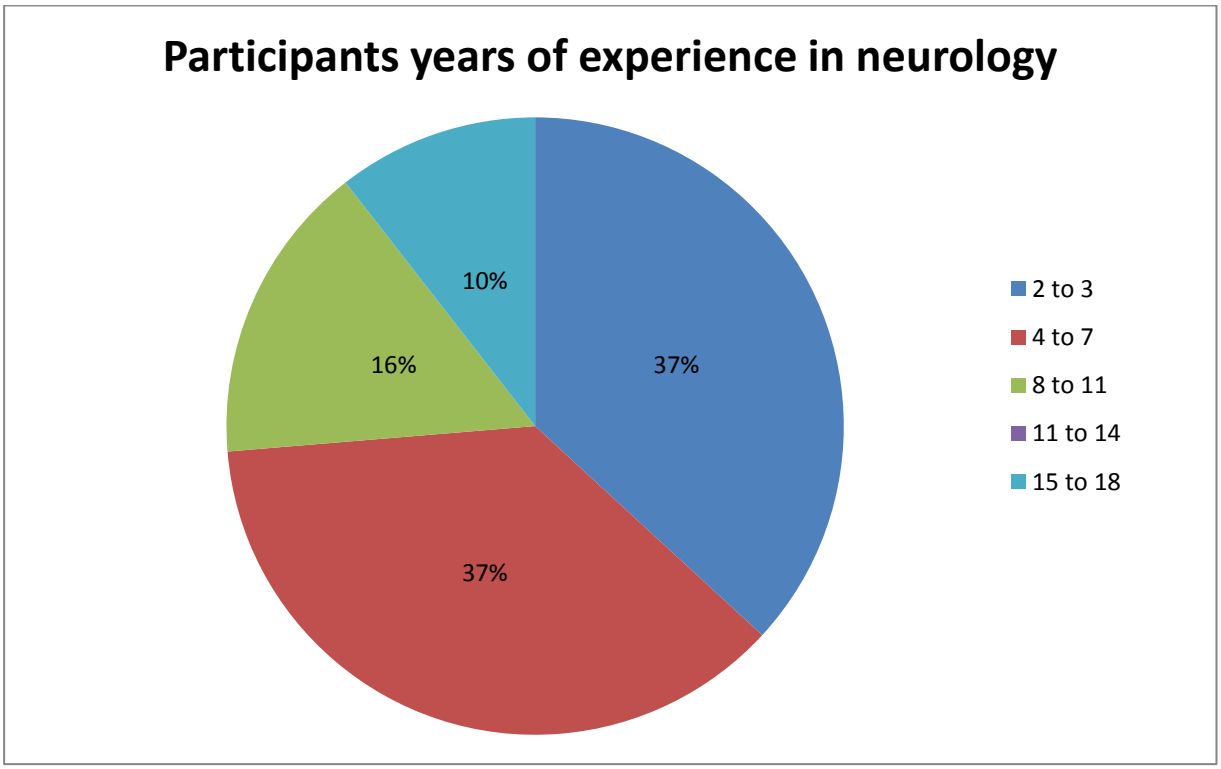

Figure 4.1: Number of years of experience in neurological occupational therapy

4.2.3 Place of undergraduate studies

As mentioned in Chapter 2, Casteleijn found that the VdTMoCA is taught at five out of eight of the universities in South Africa, at an undergraduate level.[11] Therapists that qualified from the three universities that do not teach the Model at an undergraduate level were excluded from this study. Exceptions were made if the therapist was exposed to the Model at a postgraduate level, either through postgraduate studies or courses.

It was noted that eight (42%) of the participants were University of Witswatersrand (Wits) graduates, seven (37%) from the University of Pretoria (UP), two (11%) from the University of the Freestate (UFS) and one each (5%) from the University of Kwa-Zulu Natal (UKZN) and the University of the Western Cape (UWC). Figure 4.2 below indicates the universities from which the research participants obtained their undergraduate qualification.

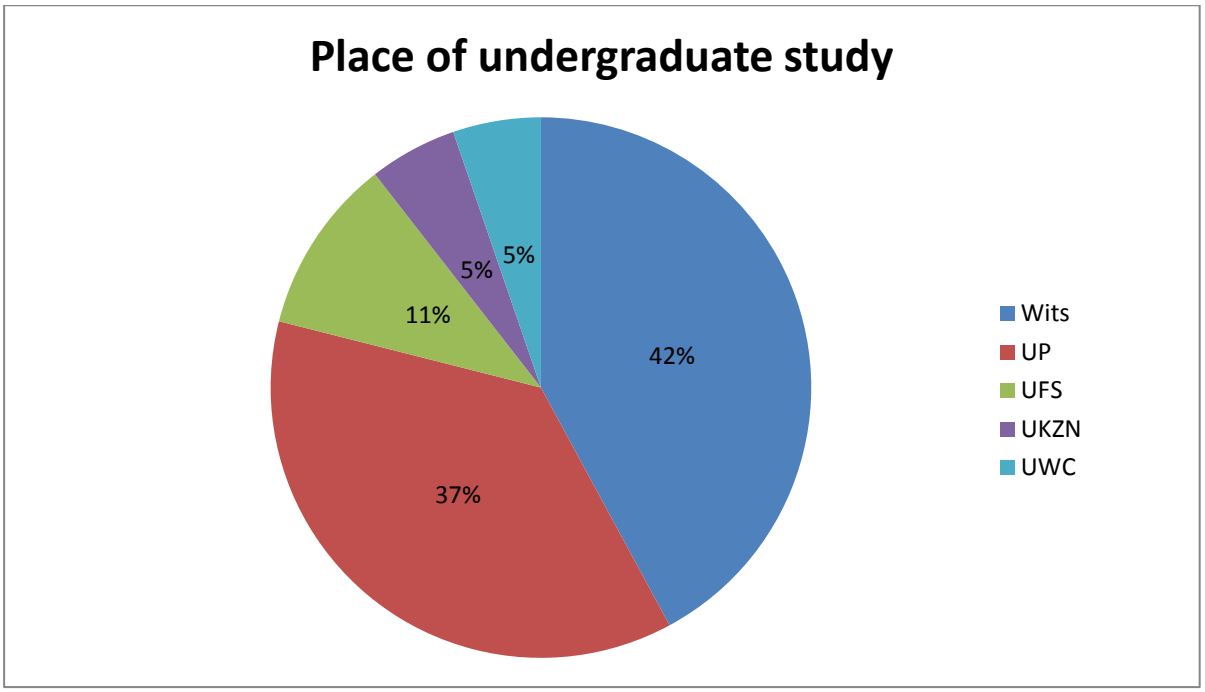

Figure 4.2: Place of undergraduate studies

4.2.4 Exposure to the Vona du Toit Model of Creative Ability

As mentioned above, as of 2013, five of the eight universities that offer undergraduate occupational therapy, teach the VdTMoCA.[29] The inclusion criteria for this research stipulated that therapists have exposure to the VdTMoCA at either an undergraduate level, postgraduate level or both. For this reason, therapists from one of the three universities were not excluded from the focus groups if they had received the relevant postgraduate exposure to the VdTMoCA. Figure 4.3 below depicts the number of participants who received exposure to the VdTMoCA at an undergraduate level only, at postgraduate level only and those that received both undergraduate and postgraduate exposure. As can be seen by the table below, 12 of the 19 participants had exposure to the VdTMoCA only at an undergraduate level, one of the 19 participants had exposure at a postgraduate level only and six of the 19 participants had exposure to the VdTMoCA at both an undergraduate and a postgraduate level.

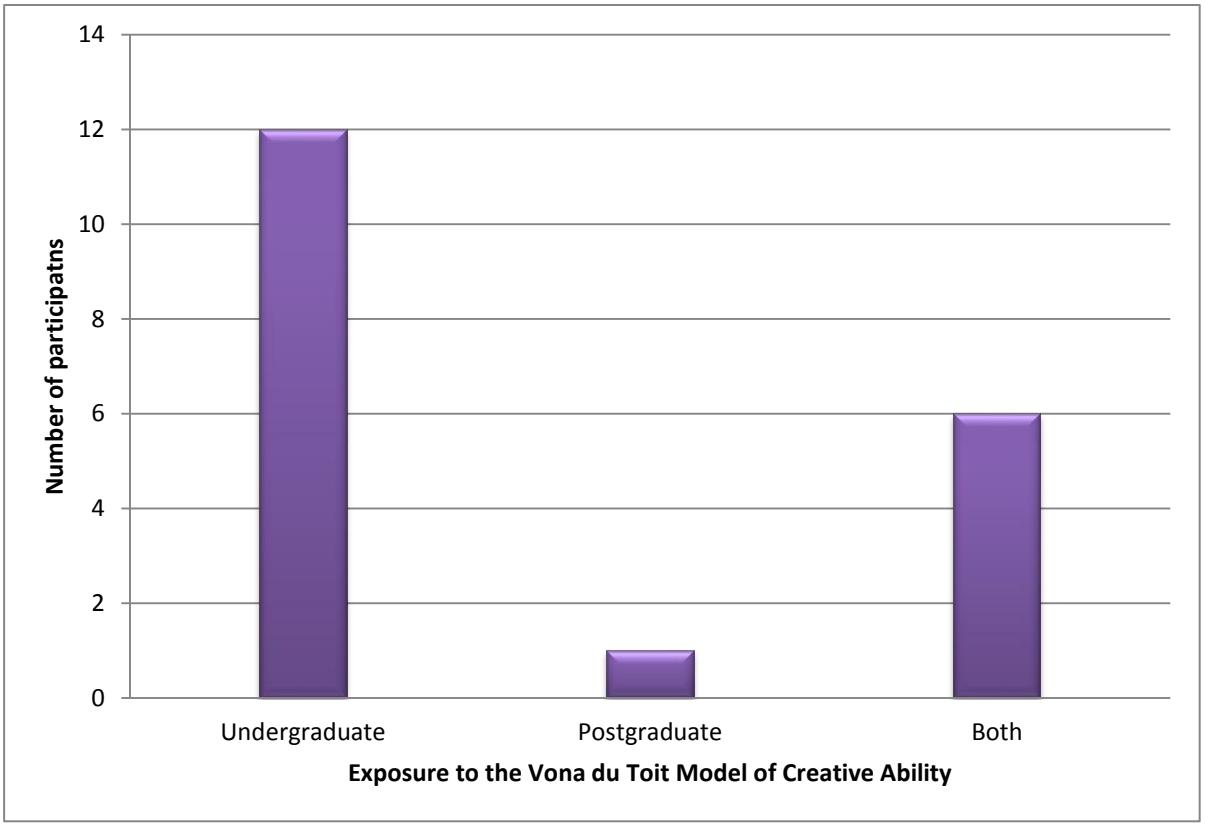

Figure 4.3: Exposure to the Vona du Toit Model of Creative Ability

4.2.5 Conclusion on demographic information

The demographic data provides valuable insights into the participants who provided the information included in the outcome measure. A total of 19 participants were involved in focus groups, with a variety of backgrounds in occupational therapy, who met the inclusion criteria. This ensured that they were able to provide a wealth of knowledge regarding neurological rehabilitation as well as regarding the VdTMoCA. The great variety of therapists from different universities, provided the focus groups with an array of opinions, thereby increasing the value of the data obtained. The next section provides an overview of the definition of neurology-specific domains and performance areas to be included in the outcome measure.

4.3 Definition of neurology-specific domains and performance areas

Prior to the commencement of the focus groups, the researcher decided on the neurological-specific domains used in the outcome measure. A combination of the review of the literature in Chapter 2 (literature by du Toit,[8] Casteleijn,[29] van den Reyden[51] and de Witt[53]) and discussions with academic and clinical expert occupational therapists (experts in neurology and the VdTMoCA) led to the decision regarding which of the domains and performance areas were included in the outcome measure.

After analysing the assessment tools and outcome measures already developed according to the VdTMoCA mentioned in Chapter 2, it became clear that the domains and performance areas used in each tool are specific to the purpose and target population (mental health care users or children) of the tool.[9,29,51,75] It also became evident that motivation and occupational performance areas are crucial elements in any occupational therapy outcome measure.[2]

Table 4.1 provides a summary of the domains and performance areas used in the focus groups and a discussion of the definition of each of these is provided thereafter.

Table 4.1: Summary of the domains and performance areas applicable to neurological occupational therapy

Domains	Performance areas
Motivation	Personal management
Action	Social ability
Quality of product/performance and task concept	Work ability
Relational contact with the body	Constructive use of free time
Relational contact with tools and materials	
Relational contact with the social world (people and situations)	
Control of anxiety	
Ability to show initiative and make an effort	

4.3.1 Domains

4.3.1.1 Motivation

Motivation is defined as the inner force that directs all behaviour, which results in the creation of products (tangible or intangible).[53] The creation of products in neurology can include tangible products such as food etc. as well as intangible products (performance) such as completing a basic activity such as hair brushing. The level of a patient's motivation is therefore crucial in all aspects of occupation engagement and, without it, initiation of tasks, execution of the steps involved and task completion is not possible.[21]

As discussed in Section 1.1, motivation is a crucial determinant of the outcome of rehabilitation in patients following an ABI.[24] Motivation affects a patient's commitment and perseverance in treatment. Therefore, low motivation negatively impacts a patient's recovery process. It is therefore a critical domain to be included in the outcome measure.

4.3.1.2 Action

Action is defined by de Witt as "The exertion of motivation into mental and physical effort, which results in occupational behaviour and the creation of a tangible or intangible end product that is the outcome of doing".[53]

The core belief of the VdTMoCA is that a person's motivation determines their action and their action is the expression of their motivation.[1,8] This core belief can be seen in other literature on motivation following an ABI.[21,24] Therefore, a patient's level of

motivation can be inferred by observing their visible action. For this reason, action is an important domain to include in the outcome measure.

4.3.1.3 Quality of product or performance and task concept

The product is the outcome of a patient's action. The quality of the product indicates the patient's ability to comply with the norms of product creation, the quality of their performance and the ability to evaluate what they have done.[8] This includes the standards that they set for themselves.[53] For this reason, during this study, the terms "product" and "performance" will be used interchangeably and together. "Task concept" refers to a person's understanding of a task as a whole and their ability to execute and complete the task appropriately.[8,53]

The quality of product within the field of neurology differs from that in psychiatry in that a neurological patient may be physically unable to complete certain movements and/or may lack the ability to plan movements or sequence activities due to specific damage in the brain. This links with the patient's concept of the task as a whole and therefore their concept of the appropriate completion of the task. For this reason, the two domains - "quality of product" and "task concept" - have been combined to incorporate all aspects of both of these domains.

4.3.1.4 Relational contact with the body

Due to the physical symptoms that can occur following an ABI, namely hemiplegia, visual neglects, decreased balance etc., an expert occupational therapist within the field of neurology indicated that a domain covering a patient's ability to contact and use their "new bodies" should be included in the outcome measure.[76] This is directly linked to the CPA's need for the domain "assistance/supervision required".[50] "Assistance/supervision refers to the amount of supervision required due to a lack of motivation and resultant action, specific to psychiatry. This is not applicable within the field of neurology as the physical assistance required may not be due to a lack of motivation, but rather a physical inability due to the nature of the injury. "Relational contact with the body" is therefore defined as how a patient uses their new body (hemiplegic side etc.) and the level of norm awareness or compliance that they display.

4.3.1.5 Relational contact with tools and materials

"Relational contact with tools and materials" is a patient's attitude to and ability to make relational contact with materials, objects and tools in the environment. It is also a patient's awareness of tool handling norms, i.e. appropriately using a toothbrush to brush teeth.[53]

This domain can be seen in the CPA[51] as well as the OTCAP,[8] and is also seen as crucial in the assessment of patients following an ABI due to the cognitive and physical limitations that can be noted as a result of their injury. Observation of a patient's "relational contact with tools and materials" can also assist the therapist in inferring the patient's corresponding level of motivation, which, as previously mentioned, is a crucial determinant in the recovery of patients following an ABI.

4.3.1.6 Relational contact with the social world (people and situations)

"Relational contact with the social world (people and situations)" is a patient's ability to communicate and interact socially in unfamiliar and familiar situations. It is seen in their ability to make friends and develop lasting relationships. The ability to read and comply with social norms in all situations also falls under this domain.[53]

An element of social interaction is seen within all the outcome measures discussed in Table 2.3. As can be seen in the APOM[29] and FLOM,[75] the handling of people and situations can be included in one domain i.e. "Relational contact with the social world". Research indicates that an ABI can cause a patient to experience difficulties controlling their social behaviour, being overfamiliar or inappropriate in social settings.[58] They may also experience language and communications fallouts which would also impair their ability to socialise.[58] It is evident from this research that social issues following an ABI are a pertinent problem that should be assessed during rehabilitation and therefore included in the outcome measure.[58]

4.3.1.7 Control of anxiety

"Control of anxiety" refers to a patient's ability to control their anxiety when faced with routine tasks as well as new challenges. It also incorporates the appropriateness and broadness of their emotional responses.[53]

An aspect of the control of anxiety can be found in most of the tools mentioned in Table 2.3 under different titles (affect, anxiety and emotional responses, control of anxiety). By observing a patient's ability to control their emotions and anxiety, a therapist is able to determine a multitude of information regarding the patient's level of functioning and therefore their level of motivation and action. Research indicates that following an ABI, patients are 2.3 times more likely to develop an anxiety disorder.[77] They are also 5.8 times more likely to develop panic disorder when compared to the general population.[77] Following an ABI, patients are also 7.5 times more likely to develop depression.[77] It is evident from this research that emotional difficulties following an ABI are a pertinent problem that should be assessed during rehabilitation and therefore included in the outcome measure.

4.3.1.8 Ability to show initiative and make an effort

Within the domain, "ability to show initiative and make an effort" it is important to note that initiative is different from exploration (found on the level of Self-Presentation). Initiative is when self-confidence and intentionality are directed at finding new successful solutions to problems or new applications of known solutions.[53] It is the ability to plan, initiate and sustain effort until an activity is done.[53]

Initiative can be severely affected following an ABI, depending on the area of the brain that was injured. A lower level of motivation will also result in an impaired ability to sustain effort. This domain is therefore applicable in the assessment of patient's following an ABI.

4.3.2 Performance areas

Occupational performance areas are seen as a crucial element of any occupational therapy assessment as emphasised in the occupational therapy process.[2] The performance areas set out by de Witt[53] are used for the purpose of this outcome measure as they incorporate all areas of occupation included in the occupational therapy process and are well defined in terms of the VdTMoCA. The definition of each of these performance areas is given below.[53]

4.3.2.1 Personal management

Personal management refers to the ability to[53]:

- Care for oneself according to the norms and culture of their society
- Acquire skills (toileting, dressing, washing etc.) and manage oneself independently within society

4.3.2.2 Social ability

Social ability is the ability to[53]:

- Interact and communicate socially with unfamiliar and familiar persons
- Form acquaintances, make friends and develop lasting, stable, mature and intimate relationships

4.3.2.3 Work ability

Work ability is the ability to[53]:

- Be productive
- Initiate projects and to follow through until completion
- Develop new ideas
- Manage oneself, workload and resources effectively in the work and home environments (open, sheltered, protective or educational setting)
- Work effectively according to norms
- Be critical of your performance through realistic judgement

4.3.2.4 Constructive use of free time

Constructive use of free time is the ability to[53]:

- Use free time in a constructive, balanced, recreational and socially acceptable manner with the intention of attaining pleasure and to de-stress

Following the definition of the domains and performance areas, focus groups were held with occupational therapists in the Gauteng Province in South Africa, as indicated in Chapter 3. The following section provides a description of the data analysis process as well as an in-depth discussion on the themes and substantiating codes developed in this study.

4.4 Objective 1 – Focus group findings and discussion

4.4.1 Overview of the themes

Guideline questions were developed in line with objective one and can be found in Annexure D. During the focus groups, participants were asked to discuss each domain and performance area mentioned in Section 4.3, per level of Creative Ability. These discussions were audio recorded for transcription purposes. An electronic data management system was not available to the researcher during the analysis process and therefore data analysis was done manually. The researcher transcribed the audio recordings of the focus groups verbatim. Each group was transcribed a second time to ensure accuracy. A code-recode procedure was then followed. The researcher proceeded to combine the codes into themes and refined these themes with substantiating codes, which then formed the basis of the information to be included in the outcome measure.

Different colours were used for different domains during the steps of thematic analysis and this continued through the developing and refining of themes. On top of this, different colours were used within the refining process in order to combine codes of the same theme. Table 4.2 below depicts the colour coding system used for the domains and performance areas.

Table 4.2: Colour coding for domains and performance areas

Colour coding	
Motivation	
Action	
Quality of product or performance and task concept	
Relational contact with the body	
Relational contact with tools and materials	
Relational contact with the social world	
Control of anxiety	
Ability to show initiative and make an effort	
Personal management	
Social ability	
Work ability	
Constructive use of free time	

Table 4.3 below depicts an extract from the colour coding used during steps three and four of TA. Codes that remained black indicated that the information contained in that code was not mentioned in more than one focus group and therefore not included. It is important to note that the colours used for the codes do not correlate with the domain and performance area colours and were used for different purposes.

Table 4.3: An extract from the colour coding of themes and substantiating codes

SELF-DIFFERENTIATION				
	Focus group 1	**Focus group 2**	**Focus group 3**	**Focus group 4**
Action	**Theme:** Incidentally constructive **Substantiating codes:** • Unintentional • Inconsistent • Working memory • Splinter skills • Mouthing	**Theme:** Incidentally constructive **Substantiating codes:** • 1 step • Feeding • Response to an input • Muscle memory • Automatic response • Unintentional • Sensory seeking	**Theme:** Incidentally constructive **Substantiating codes:** • 1 step • Immediate response • Feeding • No planning	**Theme:** Incidentally constructive **Substantiating codes:** • Unplanned construction • Instinct (grab when falling) • 1 step • Automatic

These themes and substantiating codes were then reviewed by the independent coder and expert in the field. Finally, the themes and substantiating codes were translated into domain descriptors by the researcher by combining the themes and substantiating codes with literature available on ABI's and the VdTMoCA. These domain descriptors were then included in the outcome measure.

The literature used to convert the themes and codes into domain descriptors, as well as for the discussion, includes the scales and models described in Section 2.6.

Each level of Creative Ability discussed in the focus groups is divided into the domains and performance areas described in Section 4.3. The participants were asked to discuss each domain and performance area according to each level of Creative Ability.

The results obtained from the focus groups for these domains and performance areas per level of Creative Ability, are presented as follows:

1. Question asked/prompt
2. Themes and codes identified
3. Discussion of the participants responses regarding the specific domain
4. Supporting quotations provided by the participants

Finally, each level of Creative Ability is concluded with a discussion of the results related to literature available on the VdTMoCA and ABI's.

4.5 Creative Ability Level of Tone

In a paper delivered by du Toit[8] in 1970, she stated that the first level of Creative Ability - "Tone" refers to the basic biological tone which is required for a human to survive. For mental health care users, these biological systems may function automatically despite absolute disinterest from the patient (the absence of self-directedness). Du Toit defines motivation on a level of Tone as being aimed at the will to live. Patients on a level of Tone are defenceless, incapable and dependent.[9]

Table 4.4 below provides a summary of the themes and substantiating codes derived from the focus group data for the level of Tone.

The level of Tone is divided into the domains and performance areas described in Section 4.3. The participants were asked to discuss each domain and performance area according to each level of Creative Ability and this information was then transcribed and analysed into themes and substantiating codes. These results obtained from the focus groups for the domains and performance areas for the level of Tone are presented as follows:

1. Question asked/prompt
2. Themes and codes identified
3. Discussion of the participants' responses regarding the specific domain
4. Supporting quotations provided by the participants

Finally, the level of Tone is concluded with a discussion of the focus group findings related to literature available on the VdTMoCA and ABI's.

Table 4.4: Themes and substantiating codes for Tone

TONE		
Domain	**Theme**	**Substantiating codes**
Motivation	1. Motivationally blank	• Unresponsive • Dependent
	2. Physiological maintenance	
Action	1. Pre-destructive	• No action • Purposeless, unintentional
	2. Reflexive and involuntary	• Reactions to external stimuli
Quality of product and task concept	1. None	• None
Relational contact with the body	1. No body awareness	• Involuntary response to noxious stimuli
	2. Reflexive	• Posturing in response to stimulation
	3. Neglect of the affected side	• Visual and physical neglect noted by positioning in bed
Relational contact with tools and materials	1. None	
Relational contact with the social world	1. Reflexive	• Startle response
	2. Fleeting awareness	• Responds momentarily by looking towards stimulus • Unable to sustain eye contact
Control of anxiety	1. No expression of anxiety	• Unaware
Ability to show initiative and make an effort	1. None	

4.5.1 Domain of motivation

Question asked: "Let's talk about the first level of the outcome measure – Tone. Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of their motivation?"

4.5.1.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the domain of "motivation" for the level of Tone:

Theme 1: Motivationally blank
Substantiating codes: • Unresponsive • Dependent on others and machines for survival
Discussion: According to the participants of the focus groups, patients on a level of Tone are unaware or comatose. They are totally dependent on others for anything more than simply trying to stay alive. Any participation or reaction is aimed at surviving. They are also generally dependent on medical equipment for basic life support. This decreased awareness and dependence will carry through in all areas of the patient's functioning, thereby affecting all the other domains and performance areas on a level of Tone.
Participants' supporting quotations: • *"They do not know what is happening around them. They are quite dependent in ADL's. They are on an NG-tube, they may have a PEG – worst case scenario. And if they come out of the phase, they often don't remember that they were in this phase."* • *"Very low sensory patients, they are dependent in all ADL's, often not communicating, very poor attention and alertness"* • *"… so just a low drive"* • *"… comatose"*

Theme 2: Physiological maintenance
Discussion: According to the participants of the focus groups, patients on a level of Tone have recently been injured, or sustained a severe injury that resulted in loss of consciousness. During this time, a patient is generally attached to life support machinery, heavily sedated and basically "fighting for their life". Their motivation is therefore driven by the need to survive. They are unable to focus their energy on any other aspect of existence. As one participant mentioned, they are medically unstable and present with a low drive to participate.
Participants' supporting quotations: • *"… very acute patients and a very severe stroke"* • *"… medically unstable"* • *"Basically just survive, or has to survive"* • *"I feel it is often your patients that are still in high care or ICU that are still in the acute stage, that have just had their stroke..."*

4.5.2 Domain of action

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of their action?"

4.5.2.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the domain of "action" for the level of Tone:

Theme 1: Pre-destructive
Substantiating codes: • No action • Purposeless
Discussion: According to the progression of action through the levels of Creative Ability, destructive action (seen on the level of Self-Differentiation), is preceded by the somewhat action-less "pre-destructive action" (seen on the level of Tone), as reported by the participants of this study.

Participants' supporting quotations:

- *"Non-purposeful, inconsistent…"*
- *"Not goal-directed, if there is any action. Sometimes there is no action"*
- *"Not a specific response"*
- *"I feel that there is no action"*
- *"Purposeless action"*

Theme 2: Reflexive and involuntary

Substantiating codes:

- Reactions to external stimuli
- Non-purposeful

Discussion:

The participants of the focus groups reported that following trauma to the brain, a patient can present with reflexive movements or reactions in response to a noxious sensory input. These are not purposeful reactions to a stimulus, but rather involuntary, automatic reactions. On a level of Tone, due to the fact that the patient is either comatose or in a vegetative state, they are unable to direct their movements and therefore the only response obtained would be a reflexive one.

Participants' supporting quotations:

- *"…mostly responding to sensation (internal or external)"*
- *"A physiological response, not really an intentional response"*
- *"Reactions to pain"*
- *"…external stimulus dependent"*
- *"And perhaps reflexive"*

4.5.3 Domain of quality of product or performance and task concept

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of their quality of product or performance and task concept?"

4.5.3.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the domain of "quality of product or performance and task concept" for the level of Tone:

Theme 1: None
Substantiating codes: • None • Unaware
Discussion: The domain – "quality of product or performance and task concept" relies heavily on a patient's level of arousal. According to the participants of this study, patients on a level of Tone are unresponsive and unaware and therefore unable to direct their action towards the successful creation of any product (tangible or intangible).
Participants' supporting quotations: • *"There is none"* • *"None"*

4.5.4 Domain of relational contact with the body

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of their relational contact with the body?"

4.5.4.1 Themes and codes identified

The following three themes and substantiating codes were identified to describe the "relational contact with the body" domain for the level of Tone:

Theme 1: No body awareness
Substantiating codes: • Overall poor awareness of body in space
Discussion: According to the participants, a patient's relational contact with their body will be severely impaired by their level of arousal. These patients present with poor overall awareness of their body (affected and unaffected sides included). They are unable to direct their action at anything constructive or destructive.
Participants' supporting quotations: • *"At this level, they don't have a good understanding of their own bodies and what is going on around them"* • *"…overall poor awareness of their body in space and their relation to everything else"*

Theme 2: Neglect of the affected side

Substantiating codes:

- Visual and physical neglects noted

Discussion:

According to the participants of this study, while in the vegetative state (awake but not aware),[71] it may become obvious that the patient has a physical and/or visual neglect of the affected side. This could be seen by the automatic positioning of the head to the unaffected side.

Participants' supporting quotations:

- *"No awareness of disability of symptoms of the hemiplegic side even the hemi neglect"*
- *"No attempt to use hemi side"*
- *"I think there will be a physical as well as a visual neglect. No awareness or poor awareness of the full body."*
- *"Some of the neglects, you can pick them up at this stage. That the head is pointed one way"*

Theme 3: Reflexive

Substantiating codes:

- Posturing in response to stimuli

Discussion:

Much like a patient on a level of Tone's action being reflexive in nature, the participants reported that these patients inconsistently respond to stimuli (particularly noxious stimuli) in a reflexive manner. Their relational contact with their body is therefore non-purposeful and automatic in response to specific stimuli. They are unable to control their reactions and are also unaware of their responses.

Participants' supporting quotations:

- *"..sometimes they would only respond to pain"*
- *"Noxious stimuli"*
- *"When you sometime touch them, then they posture"*
- *"Reflexive"*
- *"It is just a response to an environmental stimulus"*

4.5.5 Domain of relational contact with tools and materials

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of their relational contact with tools and materials?"

4.5.5.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "relational contact with tools and materials" domain for the level of Tone:

Theme 1: None
Substantiating codes: • None
Discussion: Relational contact with tools requires active handling of tools (be it in an appropriate or inappropriate way) and for this contact to be made, a degree of awareness is required. The participants emphasised that patients on a level of Tone are unable to make contact with even the simplest, most familiar tools due to their decreased level of arousal and poor awareness of their surroundings. This correlates well with the patient's relational contact with their body, because they are unable to direct their bodies towards any purposeful action which would be required for contact with tools and materials.
Participants' supporting quotations: • *"Purely incidental, not purposeful in any way"* • *"None"*

4.5.6 Domain of relational contact with the social world

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of their relational contact with the social world?"

4.5.6.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the domain of "relational contact with the social world" for the level of Tone:

Theme 1: Reflexive

Substantiating codes:

- Startle response

Discussion:

As with the patient's "action" and "relational contact with the body" on a level of Tone, the participants indicated that a patient's relational contact with the social world is also reflexive. As stated in the above mentioned sections, these patients respond inconsistently to external stimulation, in a reflexive, automatic manner. Patients respond with a startle response to unexpected, noxious stimuli. This is evident with sudden eye fluttering or in jerky, automatic body movements following the stimulus.

Participants' supporting quotations:

- *"…like a startle reaction, but not anything purposeful"*
- *"Reactive, it wouldn't be expressive"*
- *"Still a physiological level… reflexive"*

Theme 2: Fleeting awareness of familiar voices and faces

Substantiating codes:

- Responds momentarily by looking towards the stimulus
- Unable to sustain eye contact

Discussion:

Due to the decreased level of arousal that is so acute in patients on a level of Tone, the participants emphasised that these patients are unable to maintain an awake state for long enough to be aware of others or interact. Dependent on the areas of the brain affected by the trauma, they may present with aphasia (expressive or receptive) which would not yet be evident at this stage due to their poor level of arousal. They are unable to sustain eye contact (on the unaffected side) and despite fleeting awareness of others being present, they do not indicate any desire to interact. They are however generally able to tolerate one-sided contact with therapists or nursing staff for preventative, medical and personal-care tasks.

Participants' supporting quotations:

- *"…there is like a fleeting awareness or eye contact"*
- *"I would say no social awareness"*
- *"They could recognise, but they are not going to be able to engage"*

4.5.7 Domain of control of anxiety

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of their control of anxiety?"

4.5.7.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "control of anxiety" domain for the level of Tone:

Theme 1: No anxiety

Substantiating codes:

- Unaware

Discussion:

As a result of the comatose or vegetative state that patients on a level of Tone are in, they are unaware of their surroundings and therefore unaware that they are in hospital or that something has happened to them. The participants therefore consistently reported that patients on a level of Tone do not externally express anxiety.

Participants' supporting quotations:

- *"I am not sure if they are even aware"*
- *"I would say no level of anxiety"*
- *"…without the ability to express the anxiety"*

4.5.8 Domain of ability to show initiative and make an effort

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of their ability to show initiative and make an effort?"

4.5.8.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the domain of "ability to show initiative and make an effort" for the level of Tone:

Theme 1: None
Substantiating codes: • None
Discussion: Initiative requires the intentional direction of one's action in order to solve a problem. The participants of the focus groups indicated that patients in a comatose or vegetative state[71] are unable to participate constructively or destructively in even the most basic task and therefore do not display any initiative. They are also unable to make an effort in any task as their motivation is directed at maintaining existence (i.e. survival).
Participants' supporting quotations: • *"Zero"* • *"None"*

4.5.9 Performance area of personal management

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of personal management?"

4.5.9.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "personal management" performance area for the level of Tone:

Theme 1: Totally dependent
Substantiating codes: • No active participation
Discussion: Participation in personal management tasks requires the ability to attend to a task for its successful completion. Due to the profound decrease in the level of arousal of patients on a level of Tone, the participants emphasised that these patients are unable to actively participate in any form of personal management despite maximum facilitation from therapists. Their motivation is directed at maintaining their existence and they are therefore unaware of the need to participate in such tasks.

Participants' supporting quotations:

- *"Completely dependent"*
- *"Totally dependent"*
- *"Fully dependent"*
- *"Dependent, dependent, dependent"*

4.5.10 Performance area of social ability

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of social ability?"

4.5.10.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "social ability" performance area for the level of Tone:

Theme 1: None

Substantiating codes:

- None

Discussion:

The participants reported that the comatose or vegetative state that patients on a level of Tone are in, results in them being unaware of their surroundings and the people in it. As a result of this decrease in their level of arousal, they are unable to interact or even sustain eye contact with familiar or unfamiliar individuals.

Participants' supporting quotations:

- *"None, they can't attend"*
- *"…unable to interact"*

4.5.11 Performance area of work ability

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of work ability?"

4.5.11.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "work ability" performance area for the level of Tone:

Theme 1: None
Substantiating codes: • None
Discussion: The participants of the focus groups agreed that this performance area is not applicable to patients on a level of Tone, as they are not even able to participate in basic tasks or interact with others. They would therefore not be able to participate in any form of work related task.
Participants' supporting quotations: • *"It should be not applicable"* • *"None"*

4.5.12 Performance area of constructive use of free time

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Tone would present like in terms of constructive use of free time?"

4.5.12.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "constructive use of free time" performance area for the level of Tone:

Theme 1: None
Substantiating codes: • None
Discussion: The participants emphasised that neurological patients on a level of Tone are unaware of their surroundings and present with severely decreased level of arousal. They are unable to attend to a task (unable to initiate, execute or complete a task) despite maximum facilitation from a therapist. They are unaware of their "free time" and have no concept of leisure. Their motivation and action is directed towards maintaining existence.
Participants' supporting quotations: • *"None"* • *"No concept of leisure"*

4.5.13 Discussion on the level of Tone

There was consensus reached amongst all the participants across all four focus groups regarding the presentation of a patient following an ABI, on the level of Tone. Literature was used to substantiate the data received to ensure that it is in line with the VdTMoCA and recovery following an ABI.

The data gathered above regarding the presentation of a patient following an ABI on the level of Tone is substantiated and triangulated through the review of literature below. The literature reviewed for this purpose includes; the Disorders of Consciousness,[54] the Rancho Los Amigos Scale,[55] the Glasgow Coma Scale[56] and Maslow's Hierarchy of Needs[57]. The data is further substantiated by literature available on the VdTMoCA by du Toit[8] and de Witt.[53]

A study done by Giancino, Fins, Laureys and Schiff[54] on the Disorders of Consciousness following an ABI reported that the one of the defining clinical features of a coma include a complete loss of spontaneous or stimulus-induced arousal. There is no speech or purposeful motor activity following sensory stimulation. In the study,[54] the authors also defined the term "Vegetative state", which refers to patients who are awake but unaware of themselves or their environments. Patients in this state are completely unresponsive and dependent on others for all physical, social and survival needs.[54] While in a coma or vegetative state, it is noted that the patients' are motivationally blank as they are unaware of others around them and completely dependent on others for survival. This correlates with how du Toit[8] defines motivation on the level of Tone. Du Toit describes mental health care users on this level as those individuals whose identity is submerged by pathological and biological factors. Their motivation is aimed at surviving.[8]

Unlike the patient with psychosis (who is conscious but unable to direct their action towards creation), a patient following an ABI on the level of Tone is comatose or minimally conscious and for this reason unable to direct their action towards creation.[8] The study done by Giancino, Fins, Laureys and Schiff[54] on the Disorders of Consciousness following an ABI, indicates that patients in a coma or vegetative state are unable to participate or purposefully respond to stimulation. They are therefore unable to direct their action towards the purposeful creation of a product

(tangible or intangible), which correlates with the responses of the participants in the focus groups regarding patients on a level of Tone.[54]

The Rancho Los Amigos levels of cognitive functioning[78] (referred to as the Rancho Los Amigos Scale) is used to rate the progress of recovery following a TBI. As with the VdTMoCA[8] and the Disorders of Consciousness,[71] the Rancho Los Amigos Scale[55] also contains different levels of recovery through which patients develop post-injury. The first stage of recovery, i.e. Level 1: “No response”, states that patients presents with a complete absence of behaviour; they are unresponsive, with no action. Level 2: “Generalised response” is defined as reflexive, purposeless and dependent.[78] These patients, much like those on a level of Tone (seen in the information obtained in the focus groups of this study), are dependent on medical professionals and machinery in order to survive (in the Intensive- or High Care unit). They are motivationally blank and their motivation is directed at maintaining existence.

According to the Rancho Los Amigos Scale,[55] a patient’s action on Level 1: “No response”, is exactly as the name indicates. These patients present with a complete absence of observable change in behaviour in response to any stimulation. The action observed on Level 2: “Generalised Response” is a reflexive, automatic, non-purposeful reaction in response to a stimulus.[55,78] Both of these levels correlate with the information provided by the research participants, in terms of the action of a patient on a level of Tone.

The Glasgow Coma Scale[56] (GCS) further justifies the data collected from the focus group participants. Patients on a level of Tone would score between 0 and 5 on the GCS, labelling the injury as “severe”. Patients on this level of GCS generally present with severe impairments in cognition, physical ability and emotional and behavioural functioning. Their eye opening is dependent on the extent of their injuries, but could be none, or possibly to pressure applied to their bodies. They are unable to produce any verbal response and either present with no motor response or an extensor pattern (or reflexive pattern) of movement, much like a patient following an ABI on a level of Tone.[56]

Stage 1: “Physiological needs” of Maslow’s Hierarchy of Needs[57] is the biological needs for survival. This includes food, drink, clothing, warmth, shelter and sleep. Patients in this stage according to Maslow’s Hierarchy of Needs, focus all their energy on surviving or maintaining existence, much like the motivation of a patient following an ABI, on a level of Tone.[57]

According to du Toit[8] and de Witt,[53] the motivation of mental health care users on a level of Tone is directed at establishing and maintaining biological tone as well as establishing and maintaining the will to live. These patients are dependent, incapable and defenceless and according to de Witt,[53] require protection and to be cared for. A mental health care user on this level presents with automatic, purposeless action.[53] This is in line with the presentation of a patient following an ABI on the level of Tone, as they are unconscious and therefore present with reflexive, purposeless action.

Du Toit[8] and de Witt[53] emphasise that mental health care users on this level are fully dependent in terms of personal management, are unaware of others around them and totally incapable of performing any work or leisure related tasks, much like the data collected for patients following an ABI on the level of Tone.[8,53]

4.5.14 Conclusion on the level of Tone

For the level of Tone, patients’ severely decreased level of arousal and motivation directed towards maintaining existence greatly impacts their ability to participate in any task, relate to their body or relate to others. They are completely unaware of their surroundings, as confirmed by the Disorders of Consciousness,[71] the Rancho Los Amigos Scale,[55] the Glasgow Coma Scale[56] and Maslow’s Hierarchy of Needs[57] and in line with the VdTMoCA’s level of Tone for mental health care users.[8,53]

4.6 Creative Ability level of Self-Differentiation

Du Toit[8] described the second level of Creative Ability – “Self-Differentiation”, as the first stage where the very basic, primitive growth of a new self-awareness develops. This self-awareness is a quantitative rather than a qualitative awareness. According to du Toit,[8] on this level, a patient’s action is directed at establishing and maintaining self-awareness as a separate unit from the environment, objects and people in it.

Table 4.5 below provides a summary of the themes and substantiating codes derived from the focus group data for the level of Self-Differentiation.

The level of Self-Differentiation is divided into the domains and performance areas described in Section 4.3. The participants were asked to discuss each domain and performance area according to each level of Creative Ability. The results obtained from the focus groups for these domains and performance areas for the level of Self-Differentiation are presented as follows:

1. Question asked/prompt
2. Themes and codes identified
3. Discussion of the participants' responses regarding the specific domain
4. Supporting quotations provided by the participants

Finally, the level of Self-Differentiation is concluded with a discussion of the focus group findings related to literature available on the VdTMoCA and ABI's.

Table 4.5: Themes and substantiating codes for Self-Differentiation

SELF-DIFFERENTIATION		
Domain	**Themes**	**Substantiating codes**
Motivation	1. Egocentric	• Based on a personal, immediate need • Instant gratification
	2. To differentiate self from the environment	• Pulling tubes
Action	1. Destructive	• Restrained • Aggressive
	2. Incidentally constructive	• 1 step • Automatic action
	3. Emergence of participation	• Unplanned
Quality of product and task concept	1. Poor quality of product or performance	• Unaware of the norms • Large gross motor movements
	2. Emergence of participation in basic, physiological needs	• Automatic • 1 step
Relational contact with the body	1. Emerging body concept	• Aware of the unaffected side
	2. Neglect of the affected side	• Emerging awareness of stimulation to affected • Unable to use affected side
Relational contact with tools and materials	1. Basic, familiar tools	• Automatic
	2. Inappropriate	• Mouths everything
	3. Require maximum facilitation to engage	• Requires set-up
Relational contact with the social world	1. Fleeting or brief with familiar people	• Unable to initiate interaction • Brief eye contact on unaffected side
	2. Unaware of social norms	• Respond emotionally to familiar people • Inappropriate indication of discomfort (scream)
Control of anxiety	1. Comfort and discomfort are evident	
	2. Emotionally labile	• Exaggerated emotions
	3. Low frustration tolerance	• Easily give up
Ability to show initiative and make an effort	1. Unable to initiate	• Dependent for home exercise programme
	2. Effort in response to a physiological need	• BADL's • Engage in response to an irritant

4.6.1 Domain of motivation

Question asked: "Let's talk about the second level of the outcome measure – Self-Differentiation. Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of their motivation?"

4.6.1.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "motivation" domain for the level of Self-Differentiation:

Theme 1: Egocentric
Substantiating codes: • Instant gratification • Based on a personal, immediate need
Discussion: According to the Cambridge Advanced Learner's Dictionary and Thesaurus,[79] the term egocentric can be defined as "thinking only about yourself and what is good for you". According to the information gathered during the focus groups, the motivation of a patient on a level of Self-Differentiation can be classified as egocentric. Despite patients functioning on a level of Self-Differentiation having progressed from a level of Tone, they are still functioning on a need-based level. Unlike a patient on a level of Tone, these patients are conscious and respond to inputs. They however only respond to inputs that have a direct impact on themselves. They require instant results from their participation and are, according to the participants of the focus groups, generally motivated by a cause-and-effect type of engagement, consisting of one step. They are externally motivated by immediate needs (still primarily based on survival), such as eating.
Participants' supporting quotations: • *"They can be very impulsive"* • *"Reacting to irritants"*
Theme 2: To differentiate self from the environment in order to establish body boundaries
Substantiating codes: • Pulling tubes • Protecting self from noxious stimuli

Discussion:

The participants of the focus groups emphasised that patients functioning on a level of Self-Differentiation are motivated to differentiate themselves from others and their immediate environment. They are still not fully aware of their surroundings, but are predominantly concerned with defining their boundaries. In terms of a neurological patient they present with an increased awareness of their bodies and, despite not comprehending what has happened, they are aware that some things are different. They therefore end up pulling out tubes and acting aggressively towards people who are trying to help them in an attempt to differentiate themselves.

Participants' supporting quotations:

- *"…protecting themselves in the sensory world that doesn't make sense to them"*
- *"They will also pull out their NG because they realise that there is something, they realise it is not part of them and they are trying to differentiate"*

4.6.2 Domain of action

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of their action?"

4.6.2.1 Themes and codes identified

The following three themes and substantiating codes were identified to describe the "action" domain for the level of Self-Differentiation:

Theme 1: Destructive

Substantiating codes:

- Restrained
- Pulling out tubes
- Aggressive
- Restless
- Destructive action to their own health

Discussion:

Action on the level of Self-Differentiation is ultimately divided into two, although the intended action remains the same. According to the participants of the focus groups these patients are motivated to differentiate themselves from their surroundings and therefore attempt to exert some level of control in their lives. In an attempt to do this, they present with destructive behaviour such as pulling out tubes, pushing people away and acting impulsively. They are confused and present with poor carry over of newly learnt information, resulting in destruction or poor planning. A neurological patient on this level may be restrained due to this destructive behaviour, as they can be a danger to their own health as a result of their poor insight.

Participants' supporting quotations:

- *"Ja, [I] like the unsafe, impulsive, aggressive, restless action"*
- *"Pulling, pushing, NG-tubes, catheters, PEG's"*
- *"There might be a restraint because of that kind of behaviour"*
- *"No purpose"*

Theme 2: Incidentally constructive

Substantiating codes:

- 1 step
- Automatic and unintentional
- Splinter skills (eating)

Discussion:

The participants reported that, much like the above mentioned destructive action, incidentally constructive action occurs without intentional planning from the patient. In an attempt to differentiate themselves and their new body, the patient may incidentally construct something. This could be as a direct result of being destructive – for example, while hitting a staff member away with a hair brush, the patient may find their hair and give their hair one appropriate brush. This action is completely unplanned and short-lived (generally only one step) before the destructive action or lack thereof continues.

Participants' supporting quotations:

- *"It is obviously still one step and immediate response"*
- *"There is no planning, it just happens"*
- *"They open their mouth when the spoon comes"*
- *"You know, it is like that muscle memory thing, you know like splinter cells. Working memory"*
- *"Something that just ends up being constructive somehow"*
- *"It is almost like an automatic response – if they are cold, pull the blanket up"*

Theme 3: Emergence of participation

Substantiating codes:

- Attempts to engage
- No plan

Discussion:

In direct comparison to a patient on a level of Tone, these patients present with an emergence of participation. They are motivated to do something (regardless of the outcome), unlike the completely sedentary, unaware previous level. This participation is generally in response to direct external stimuli, unplanned and approximately only one step.

Participants' supporting quotations:

- *"…I think about those patients who are more active than the Tone patients"*
- *"…the motivation is that they are trying to do something"*
- *"…there is an action and you are trying to attempt something with this action, but it is not resulting in the desired outcome"*
- *"They are at least attempting to engage in some way"*

4.6.3 Domain of quality of product or performance and task concept

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of their quality of product or performance and task concept?"

4.6.3.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "quality of product or performance and task concept" domain for the level of Self-Differentiation:

Theme 1: Emergence of participation in basic, physiological need tasks
Substantiating codes: • Survival • Eating • Participation in response to a need (hunger, thirst or cold) • 1 step • Automatic, in a familiar task • Not a conscious effort
Discussion: The participants of the focus groups were in agreement that patients on a level of Self-Differentiation participate automatically in basic tasks, generally aimed at fulfilling a physiological need. The major focus of their active engagement is in feeding tasks as eating is a basic need for survival. They may open their mouth as a spoon gets closer or spontaneously pick up a spoon in an attempt to eat. The quality of these tasks remains poor despite this emergent participation.
Participants' supporting quotations: • *"Ja, probably only like 1 step"* • *"And it would also be like very basic tasks"* • *"…except with feeding. It is such a basic thing"* • *"Task concept in terms of feeding, I almost feel like they understand the eating"*
Theme 2: Poor quality of product or performance
Substantiating codes: • Unaware of the norms • Large gross motor movement

Discussion:

Due to their decreased awareness of their surroundings, the participants emphasised that patients on a level of Self-Differentiation are unaware of the norms regarding product creation or performance. They do not intentionally participate in any tasks and therefore are not worried about the quality of their performance. Their action is generally destructive leading to poor, rather adverse effects rather than construction or good quality.

Participants' supporting quotations:

- *"I don't think they care about quality yet"*
- *"No quality of product"*

4.6.4 Domain of relational contact with the body

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of their relational contact with the body?"

4.6.4.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with the body" domain for the level of Self-Differentiation:

Theme 1: Emerging body concept

Substantiating codes:

- Aware of the unaffected side
- Uses unaffected side in tasks

Discussion:

In direct comparison to the level of Tone, the participants indicated that patients on a level of Self-Differentiation are more awake and aware of their surroundings. They are developing a basic understanding that something is different which results in the destructive behaviour mentioned above. They are particularly aware of pain or discomforts caused and respond directly to these inputs. They use their unaffected upper limb to perform these destructive or incidentally constructive actions, despite this being totally unplanned.

Participants' supporting quotations:

- *"Maybe they are experimenting with their body parts"*
- *"Automatic movements"*
- *"They are aware that something is wrong, some of them. Very basic"*
- *"Aware of discomfort"*
- *"Developing"*
- *"Aware that their body is different"*

Theme 2: Neglect of the affected side

Substantiating codes:

- Emerging awareness of stimulation to affected side
- Unable to use affected side in tasks

Discussion:

As reported by the participants of the focus groups, patients who present with one side more affected due to the ABI are unable to make use of this side and tend to neglect it during action. They may present with an emerging awareness of a noxious stimulation to the affected side, although they are not able to localise it or name it. They are aware of the obvious such as objects within their immediate environment or familiar faces.

Participants' supporting quotations:

- *"But I think it is very emerging. Like awareness of pain on that side or awareness of you stimulating that side. Like that is the only time that they are aware of that side."*
- *"There is no way you are going to get them crossing the midline if there is a slight visual neglect"*

4.6.5 Domain of relational contact with tools and materials

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of their relational contact with tools and materials?"

4.6.5.1 Themes and codes identified

The following three themes and substantiating codes were identified to describe the "relational contact with tools and materials" domain for the level of Self-Differentiation:

Theme 1: Basic, familiar tools
Substantiating codes: • Automatic • Uses daily, familiar tools (spoon)
Discussion: As with "task concept", the participants of this study indicated that patients on a level of Self-Differentiation retain an awareness of the basic tools required for familiar tasks, generally in response to a physiological, immediate need. The interaction with these tools is automatic, with no planning or intentionality. They are unable to name these tools. This can be seen mainly in eating tasks.
Participants' supporting quotations: • *"Well sometimes they will reach for them, but early tool use"* • *"They understand a spoon"* • *"Spoon"* • *"Knowing to put their head on the pillow"*
Theme 2: Inappropriate use
Substantiating codes: • Mouths everything
Discussion: As a result of their poor task concept and destructive action, patients on a level of Self-Differentiation use tools and materials inappropriately. These patients mouth any material they are given, possibly to fulfil a basic, physiological need (hunger), despite soap or a face cloth being inappropriate foods.
Participants' supporting quotations: • *"Inappropriate use of tools"* • *"They might not use it for the right thing, they may not use the face cloth to wash, they may eat the face cloth"* • *"…they are the ones eating soap, wash cloths, putting lotion in their hair"*

Theme 3: Requires maximum facilitation to engage with tools
Substantiating codes: • Requires set-up
Discussion: The participants were in agreement that patients on a level of Self-Differentiation are unable to independently engage with tools or materials. They will remain passive or respond directly to an irritant unless directed with maximum facilitation. Following this facilitation, interaction with the tool and material is short lived and not necessarily appropriate. Due to poor body awareness, hand over hand facilitation may be required for interaction with tools and materials.
Participants' supporting quotations: • *"It is not even an awareness if you don't make them aware"* • *"…maximal assistance"* • *"They won't seek it"*

4.6.6 Domain of relational contact with the social world

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of their relational contact with the social world?"

4.6.6.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with the social world" domain for the level of Self-Differentiation:

Theme 1: Fleeting or brief contact with familiar people
Substantiating codes: • Fleeting awareness of others • Brief eye contact on the unaffected side • Turns towards familiar people • Unable to initiate interaction

Discussion:

According to the participants patients on a level of Self-Differentiation remain generally unaware of others, although they might respond briefly to familiar people on their unaffected side. This is different from their awareness of unfamiliar people who they often do not respond to at all. They are however unable to initiate interaction with either familiar or unfamiliar people. Their social interaction entails brief eye contact and possibly monosyllabic interaction or basic gestures.

Participants' supporting quotations:

- *"They may be able to attend briefly"*
- *"Different responses for known and unknown people"*
- *"If you say hello, they may localise visually to you"*
- *"Emerging social contact"*

Theme 2: Unaware of social norms

Substantiating codes:

- Respond emotionally to familiar people
- Inappropriate indication of discomfort (screaming, crying or aggression)

Discussion:

The participants indicated that patients on a level of Self-Differentiation are largely unaware of any norms, including social norms. They are unable to reciprocate interactions and respond inappropriately a lot of the time (i.e. over-emotional when family members enter the room or screaming if they are uncomfortable despite other patients being nearby).

Participants' supporting quotations:

- *"There is now also active resistance, now say no, shaking their head, turning away from a stimulus"*
- *"These are the patients that are moaning and screaming in the ward"*
- *"I would say that their social interaction is egocentric"*
- *"…won't make you aware that they need to use the toilet"*
- *Yes, it will be kind of an inappropriate response"*

4.6.7 Domain of control of anxiety

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of their control of anxiety?"

4.6.7.1 Themes and codes identified

The following three themes and substantiating codes were identified to describe "control of anxiety" domain for the level of Self-Differentiation:

Theme 1: Emotionally labile
Substantiating codes: • Exaggerated emotions
Discussion: Due to their increased awareness that something is a different, patients on a level of Self-Differentiation present with an increase in their levels of anxiety and emotion. They are unable to control these emotions and this often results in emotional lability.
Participants' supporting quotations: • *"All exaggerated"* • *"I am just thinking of those patients who are just irritable and [groany]"* • *"…emotionally labile at this stage"*
Theme 2: Comfort and discomfort are evident
Discussion: The participants emphasised that patients on a level of Self-Differentiation present with an increased awareness of their body and therefore comfort and discomfort. They express these emotions, although generally inappropriately. They are unable to name their discomfort and therefore often just scream or cry without any direct indication of exactly what is bothering them.
Participants' supporting quotations: • *"…comfort and discomfort are evident"* • *"You can instantly recognise if they are uncomfortable"*
Theme 3: Low frustration tolerance
Substantiating codes: • Easily give up or shut off

Discussion:

The participants of the focus groups emphasised that patients on a level of Self-Differentiation often present with low frustration tolerance. This could be due to their decreased insight into what has happened to them, as well as the many physical irritants present i.e. feeding tubes, restraints and machinery. They often get frustrated in therapy tasks because they do not understand the purpose of participating or if the activity is graded too high for their level of functioning. This confusion often results in patients on this level refusing therapy or becoming aggressive.

Participants' supporting quotations:

- *"Like with tone, there is no modulation"*
- *"…or be completely frustrated during the session"*

4.6.8 Domain of ability to show initiative and make an effort

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of their ability to show initiative and make an effort?"

4.6.8.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "ability to show initiative and make an effort" domain for the level of Self-Differentiation:

Theme 1: Unable to initiate

Substantiating codes:

- Unable to problem solve
- Dependent for carrying out a home exercise programme

Discussion:

Patients on a level of Self-Differentiation are unable to initiate any task according to the participants. They are unaware of the need to participate in tasks and require maximum and possibly hand over hand facilitation to participate in tasks. They are able to initiate an action in direct response to a stimulus however this response is completely unplanned and generally destructive in nature.

Participants' supporting quotations:

- *"Only with external stimulation, when you direct it"*
- *"Definitely no initiative"*
- *"I think it is incidental, it happens without them planning to show initiative"*

Theme 2: Effort in response to a physiological need

Substantiating codes:

- Engages in BADL's
- In response to a need (food)

Discussion:

As mentioned previously, the focus group participants indicated that patients on a level of Self-Differentiation are able to participate in a task that is directed at a basic, physiological need, such as hunger or irritation. This is observed in the automatic opening of their mouth in response to a spoon or the pulling out of tubes in response to an irritant. This can therefore be seen as the beginning stages of effort shown.

Participants' supporting quotations:

- *"It could be for basic needs, like if your hands are cold"*
- *"Scratch a nose, pull a tube that is irritating them"*
- *"…in response to a basic need"*
- *"Effort is directed to pain and discomfort"*

4.6.9 Performance area of personal management

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of personal management?"

4.6.9.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "personal management" performance area for the level of Self-Differentiation:

Theme 1: Dependent

Substantiating codes:

- Unable to initiate
- Poor awareness of the need to perform self-care tasks

Discussion:

The focus group participants indicated that patients on a level of Self-Differentiation remain fully dependent for all personal management tasks. They are unable to initiate any tasks and have a poor awareness that there is a need to perform such tasks as they are egocentric and continue to be focused on physiological functions (such as fulfilling basic needs).

Participants' supporting quotations:

- *"Maximum assistance"*
- *"Still need maximum physical assistance"*
- *"When you dress them, they will sometimes then suddenly push their arm through"*
- *"Dependent in toileting"*

Theme 2: Able to participate with maximum facilitation

Substantiating codes:

- 1 step

Discussion:

As a result of their increased awareness and inconsistent ability to participate in 1 step tasks, the focus group participants emphasised that patients on a level of Self-Differentiation are able to show momentary engagement in basic personal management tasks with maximum and possibly hand over hand facilitation from the therapist. This engagement may not be constructive, as mentioned previously, but can be seen as momentary active engagement in a task none-the-less.

Participants' supporting quotations:

- *"…there is a level of participation"*
- *"Hand over hand, one step"*
- *"Personal management is not important for them at this stage"*

4.6.10 Performance area of social ability

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of social ability?"

4.6.10.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "social ability" performance area for the level of Self-Differentiation:

Theme 1: Egocentric
Substantiating codes: • Not reciprocal • Interaction is based on their own needs
Discussion: According to the participations, interaction on the level of Self-Differentiation is egocentric, as these patients remain focused on their personal needs. These patients are generally unable to appropriately express their needs and therefore tend to inappropriately express these with screams or cries despite other people being in the near vicinity. They are unable to reciprocate interactions, even with familiar people.
Participants' supporting quotations: • *"…verbalise comfort and discomfort because they will tell you they want to eat or I am hungry"* • *"Still egocentric"* • *"They will not be reciprocal"*
Theme 2: Able to recognise familiar people
Substantiating codes: • Turns towards familiar people
Discussion: As mentioned in "Relational contact with the social world", patients on this level are able to recognise familiar people and often respond by turning towards them or making brief eye contact. This engagement often does not extend to unfamiliar people. Despite this recognition, they are unable to initiate interaction with familiar or unfamiliar people.

Participants' supporting quotations:

- *"They recognise their beloved family members and socially look towards them"*
- *"...will make eye contact with familiar people and try to talk to them but it might not make sense"*

4.6.11 Performance area of work ability

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of work ability?"

4.6.11.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "work ability" performance area for the level of Self-Differentiation:

Theme 1: None

Substantiating codes:

- None

Discussion:

As a result of their poor initiative, poor task concept, overall confusion and decreased awareness of the norms, the participants were in agreement that patients on a level of Self-Differentiation are unable to participate in any form of work-related activity.

Participants' supporting quotations:

- *"None"*
- *"There is not much task concept"*

4.6.12 Performance area of constructive use of free time

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Differentiation would present like in terms of constructive use of free time?"

4.6.12.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "constructive use of free time" performance area for the level of Self-Differentiation:

Theme 1: None
Substantiating codes: • None
Discussion: The participants indicated that despite the increase in their level of arousal and awareness, patients on a level of Self-Differentiation are unaware of the concept of free time, unable to initiate any constructive tasks and can only actively perform one step of a task. They therefore do not have any constructive use of their free time, but rather tend to stare aimlessly or sleep all day unless facilitated by others to participate.
Participants' supporting quotations: • *"Not yet"* • *"They won't even look at the TV in the ward"* • *"They could sleep all day"*

4.6.13 Discussion on the level of Self-Differentiation

The data provided by all the participants across the four focus groups correlated well and therefore it can be noted that data saturation was reached for all the domains and performance areas for the level of Self-Differentiation. Literature was used to substantiate the data collected to ensure that it is in line with the VdTMoCA and recovery following an ABI.

As with the level of Tone, the Disorders of Consciousness,[54] Rancho Los Amigos Scale,[78] Glasgow Coma Scale[56] and Maslow's Hierarchy of Needs[57] provide strong evidence substantiating the data collected in the focus groups for the level of Self-Differentiation. The data collected in the focus groups is further substantiated with the information provided by du Toit[8] and de Witt[53] on the VdTMoCA for mental health care users and children.

According to the Disorders of Consciousness, the state following the comatose and vegetative state is labelled the “Minimally Conscious State” (MCS).[71] This state is characterised by minimal or brief and fleeting responses. Despite the inconsistent nature of these responses, they are consciously driven and are representative of more than reflexive responses in response to stimulation. In order to diagnose someone as being in an MCS, they should present with clearly discernible evidence of[54]:

- Recognisable “yes-no” responses (gestural or verbal)
- Simple following of commands
- Non-reflexive actions that can be selectively triggered

A pivotal feature in the diagnosis of MCS is the response inconsistency.[54]

In a case study done by Cochrane and Williams,[71] a patient in an MCS following a TBI was described. The patient was able to perceive pain and was aware that something was different in his surroundings and his body, although he was unable to communicate his experience. He was able to inconsistently open his eyes to a familiar voice and even look towards the stimulus (if the stimulus was on his unaffected side). While in this state, the case study patient continued to be reliant on feeding tubes and total assistance from nursing staff for his physical needs.[71]

The data obtained during the focus groups of this study on the level of Self-Differentiation lines up well with the presentation of a patient in an MCS. The data presented in Table 4.5 and the information given regarding the MCS patient, correlate in many aspects. These aspects include:

- egocentric motivation which results in an unplanned and brief, one step action
- evidence of fleeting or brief contact with familiar people
- the display of comfort or discomfort
- poor problem solving
- complete dependence for all self-care tasks

The data obtained in the focus groups for the level of Self-Differentiation is further substantiated by Level 3: “Localised response” and Level 4: “Confused – Agitated” from the Rancho Los Amigos Scale.[78]

According to the Rancho Los Amigos Scale, Level 3: ”Localised response”, is characterised by the following[55,78]:

- Turning towards stimulation (brief eye contact)
- Responding to discomfort (pulling out tubes)
- Inconsistent responses
- Responding only to familiar people
- Requiring total assistance for all tasks

According to the Rancho Los Amigos Scale, Level 4: “Confused – Agitated” is characterised by the following[55,78]:

- Removal of restraints or tubes
- Unplanned action
- Absent short-term memory (confusion and disorientation)
- Labile emotions
- Aggression
- Poor sustained effort
- Difficulty verbally expressing self
- Requiring maximum assistance for all tasks

The characteristics mentioned above strongly substantiate the data obtained from the focus groups. The Rancho Los Amigos Scale describes patients on level 3 or 4 as destructive. This is seen in the removal of tubes and their aggressive behaviour. It can be seen from the information above that, just like patients on a level of Self-Differentiation, patients on level 3 or 4 only respond to familiar people and present with unplanned one step action, labile emotions, an inability to initiate, problem solve or sustain effort and total dependence in terms of self-care tasks.[78]

The Glasgow Coma Scale[56] (GCS) further justifies the data collected from the focus group participants. Patients on a level of Self-Differentiation would score between 6 and 9 on the GCS, labelling the injury as “moderate to severe”.[56] Patients on this level of GCS generally present with moderate to severe impairments in cognition, physical ability and emotional and behavioural functioning. Their eye opening is in response to pressure to a body part or sound, they present with incoherent speech and are unable to use their affected upper limb functionally. During this stage, patients are also unable to use their unaffected side consistently.[56] This correlates with the data collected and analysed regarding patients on a level of Self-Differentiation as they are confused, present with fluctuating participation, have unplanned movements, require total assistance and are totally unaware of others and the norms.

As mentioned in the discussion for the level of Tone in Section 4.5.13, Stage 1: “Physiological needs” of Maslow’s Hierarchy of Needs[57] is the biological need for survival. This includes food, drink, clothing, warmth, shelter and sleep. Despite these patients having progressed from the physiological maintenance seen on the level of Tone, patients on a level of Self-Differentiation continue to function on a need-based level. Unlike the reflexive patient on a level of Tone, patients on this level are able to perform one step of a task aimed at a basic need. Much like a patient on stage 1, patients following an ABI on a level of Self-Differentiation act only in response to basic needs, as seen in Table 4.5 – opening their mouth in response to food, pulling up a blanket when they are cold etc.[57]

Lastly, the data obtained in the focus groups is substantiated by the information provided by du Toit[8] and de Witt[53] on the level of Self-Differentiation for mental health care users and children. Although the discussions in the focus groups were focused on developing domain descriptors for a patient with an ABI, the facilitator ensured that the discussion remained in line with the VdTMoCA through the use of visual representations and recapping of the levels of Creative Ability in psychiatry. This can be seen in the underlining elements of the data obtained. The motivation of patients following an ABI on a level of Self-Differentiation is egocentric, with destructive and incidentally constructive action which is in line with the information provided by du Toit.[8]

The data indicates that patients with an ABI, much like mental health care users, require total assistance for all tasks and can participate in one step of a task, either destructively or incidentally constructively, with maximum facilitation from the therapist. Both psychiatric and neurological patients are egocentric on the level of Self-Differentiation, are unable to participate in any leisure or work related tasks and present with no task concept or initiative.[53]

4.6.14 Conclusion on the level of Self-Differentiation

For the level of Self-Differentiation, patients are focused on differentiating themselves from their environment and others. Patients remain confused and unable to plan or problem solve, which results in destructive or incidentally constructive action in an attempt to differentiate themselves. This destructive action can be seen throughout the domains and performance areas, with aggressive behaviour, poor frustration tolerance and overall poor effort displayed. Patients display an emerging awareness of their surroundings and their body which results in an attempt to differentiate themselves as confirmed by the MCS in the Disorders of Consciousness,[54] level 3 and 4 of the Rancho Los Amigos Scale,[78] the Glasgow Coma Scale,[56] Maslow's Hierarchy of Needs[57] and information provided by du Toit[8] and de Witt[53] on the VdTMoCA for patients on a level of Self-Differentiation.

4.7 Creative Ability level of Self-Presentation

In the paper that du Toit[8] delivered in 1970, du Toit referred to the third level of Creative Ability – "Self-Presentation", as those patients that give evidence of a desire to present the self. On this level, the patient's action is directed at the presentation of self to others. It is also directed at developing the most basic and fundamental skills in social interaction. They explore the abilities of their body, their ability to control the environment and lastly their ability to be constructive. Patients on a level of Self-Presentation present with an emerging awareness of the norms set by society, but they are unable to comply with these norms.[8]

Table 4.6 below provides a summary of the themes and substantiating codes derived from the focus group data for the level of Self-Presentation.

The level of Self-Presentation is divided into the domains and performance areas described in Section 4.3. The participants were asked to discuss each domain and performance area according to each level of Creative Ability. The results obtained from the focus groups for these domains and performance areas for the level of Self-Presentation are presented as follows:

1. Question asked/prompt
2. Themes and codes identified
3. Discussion of the participants' responses regarding the specific domain
4. Supporting quotations provided by the participants

Finally, the level of Self-Presentation is concluded with a discussion of the focus group findings related to literature available on the VdTMoCA and ABI's.

Table 4.6: Themes and substantiating codes for Self-Presentation

SELF-PRESENTATION		
Domains	**Themes**	**Substantiating codes**
Motivation	1. To present self	• Attempts to participation
	2. Unsure, extrinsically motivated	• Requires supervision and positive feedback
Action	1. Explorative, facilitated	• Unplanned • Exploring their body and senses
	2. 1-2 steps with global instructions, 3-4 steps with step by step instructions (including preparatory movements)	
Quality of product and task concept	1. Partial task concept	• Familiar activities • Prompting required in all phases of task concept
	2. Poor quality of product or performance	• Unable to evaluate • Poor task completion
Relational contact with the body	1. Increased awareness of abilities	• Able to use unaffected as needed • Will compensate with unaffected
	2. Learned non-use develops	• Facilitation required for full body awareness
Relational contact with tools and materials	1. Basic tools and materials	• Able to identify familiar tools • Explore with unaffected
	2. Aware but not compliant with norms of handling	• Poor quality of use
Relational contact with the social world	1. Egocentric	• Based on needs and wants
	2. Automatic speech	• Pleasantries
	3. Emerging intent to interact	• Aware of others, unable to initiate interaction • Able to interact with therapist
Control of anxiety	1. Emotionally labile, poor emotional control	• Unable to self-modulate
	2. Fearful, low self-esteem	• Increased insight into fallouts • Requires success
Ability to show initiative and make an effort	1. Poor frustration tolerance, unable to sustain effort	• Low perseverance
	2. Poor initiative	• Makes and effort, but unplanned • Dependent on others to follow home exercise programme

4.7.1 Domain of motivation

Question asked: "Let's talk about the third level of the outcome measure – Self-Presentation. Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of their motivation?"

4.7.1.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the domain of "motivation" for the level of Self-Presentation:

Theme 1: To present self
Substantiating codes: • Attempts to participate • Motivation is developing towards constructive action
Discussion: The participants were in agreement that patients on a level of Self-Presentation are motivated to present themselves. Different from the psychiatric patients on this level, neurological patients are motivated to present themselves physically and develop an understanding of their new body. They attempt to participate in a variety of tasks in order to determine what they are now capable of doing. Due to cognitive fallouts also seen after suffering an ABI, these patients may present with almost "child-like", wishing to gain the attention of familiar people, often done in an egocentric way.
Participants' supporting quotations: • *"A lot more active than the previous level"* • *"There is an intent to participate"* • *"They are driven to start to be aware of their ability or inability"* • *"If you do their nails, they will show everyone"* • *"And they want to present themselves to you. If you are in the ward round, they want to wave to you."*
Theme 2: Unsure, externally motivated
Substantiating codes: • Requires supervision and positive feedback

Discussion:

Patient's on a level of Self-Presentation are aware of the norms set by society, but not compliant with these norms. They are therefore occasionally aware that their actions are not meeting these norms which results in an uncertainty. They are externally motivated by positive feedback and affirmation as well as by their personal needs and will often not participate unless participation has an external motivator.

Participants' supporting quotations:

- *"…they are very unsure. You need to be constantly there"*
- *"but they are definitely unsure so they become quite anxious"*
- *"They don't really handle negative feedback"*
- *"It would be extrinsic motivation. It needs to have a positive outcome."*

4.7.2 Domain of action

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of their action?"

4.7.2.1 Themes and codes identified

The following three themes and substantiating codes were identified to describe the domain of "action" for the level of Self-Presentation:

Theme 1: Explorative

Substantiating codes:

- Unplanned
- Exploring their body
- Fearful and unsafe
- Testing the limits of their new body (standing up without the necessary strength)

Discussion:

Unlike the previous two levels, it became evident during the focus groups that patients on a level of Self-Presentation are able to engagement in a task. On this level, the engagement is explorative in nature. Exploration in a patient with an ABI can be seen in the way that they perform different functional tasks and how they use their new body. They are exploring new ways of performing tasks and movements that they could previously do, which can sometimes lead to solutions or failure. As a result of this exploration, their movements are often uncoordinated and unsafe, although not intentionally destructive. They are unable to initiate interaction with tools, materials or others independently and therefore require facilitation and prompting from others to initiate this explorative action.

Participants' supporting quotations:

- *"Perhaps with bed mobility or rolling to get up you would see the explorative action"*
- *"I think exploring the sensation of the object, tasting, feeling face cloth and smells"*
- *"…they will stand and they have poor knee control and will fall. At least it is not completely destructive action of just standing with no awareness."*
- *"They are testing"*
- *"Very unplanned"*

Theme 2: Facilitated

Substantiating codes:

- Requires prompting and set-up

Discussion:

Patients on a level of Self-Presentation are unable to initiate interaction with tools, materials or others independently and therefore require facilitation and prompting from others to initiate the explorative action that is so evident on this level.

Participants' supporting quotations:

- *"They still need constant supervision throughout those steps"*
- *"I think exploring the sensation of the object, tasting, feeling face cloth and smells"*
- *"…they will stand and they have poor knee control and will fall. At least it is not completely destructive action of just standing with no awareness."*

Theme 3: 1-2 steps with global instructions
3-4 steps with step by step instructions (including preparatory movements)

Discussion:

Participants indicated that engagement in tasks develops on the level of Self-Presentation. These patients are able to execute one to two steps of a task independently once the task has been set-up and they have been prompted to participate. If the patient is given step by step instructions with more guidance in the task, they will be able to perform three to four steps of a task, with preparatory movements counted in the number of steps, i.e. maintain an upright seated position while performing a small part of a task.

Participants' supporting quotations:

- *"I would still put it at 1-2 steps with better movement. Because 3-4 steps is very high."*
- *"I get that but maybe a part of the step is their ability to (1) sit up without support, (2) to keep that without falling over, (3) I can take my hand to my face and wipe one, (4) opening the lotion"*
- *"Like a 2 step task and familiar"*

4.7.3 Domain of quality of product or performance and task concept

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of their quality of product or performance and task concept?"

4.7.3.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "quality of product or performance and task concept" domain for the level of Self-Presentation:

Theme 1: Partial task concept

Substantiating codes:

- Familiar activities
- Prompting and set-up is required in all phases of task concept
- Poor task completion

Discussion:

As mentioned previously, participants indicated that patients on a level of Self-Presentation are able to engage in a familiar task that is facilitated and set-up for them. Despite being unable to initiate a task independently, they are able to perform some steps of execution. They present with poor awareness of task completion and therefore require facilitation throughout all the steps of task concept, despite their engagement in the task.

Participants' supporting quotations:

- *"…it is partial task concept because there is an idea of a need. The important thing there is familiar activity."*
- *"They need assistance throughout all phases of task concept"*
- *"They are not going to do the whole task on their own"*

Theme 2: Poor quality of product or performance

Substantiating codes:

- Messy
- Unable to evaluate
- Developing awareness of the norms but unable to comply

Discussion:

Despite their engagement in tasks, patients on a level of Self-Presentation are unable to meet the norms set by society. They are unable to evaluate their end product and are more interested in the process of participating than the quality of performance or end product.

Participants' supporting quotations:

- *"…not going to evaluate the quality of the product"*
- *"Because they are testing what they can do, the quality will not be great"*
- *"It is more about the action just being completed, that gratification – it is done"*
- *"…there is no sense of evaluating"*

4.7.4 Domain of relational contact with the body

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of their relational contact with the body?"

4.7.4.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with the body" domain for the level of Self-Presentation:

Theme 1: Increased awareness of abilities with improved body concept

Substantiating codes:

- Uses unaffected side as needed
- Will compensate

Discussion:

As previously mentioned, patients on a level of Self-Presentation are aware of the norms but unable to comply with them. They therefore present with a greater awareness of their abilities and limitations, allowing them to compensate for fallouts they may still suffer from, i.e. flaccid upper limb. They are able to use their unaffected limb in functional tasks.

Participants' supporting quotations:

- *"They are ok with it, they are getting more used to people being there, receiving therapy. They are more accommodating."*
- *"I think they are starting to have a much better concept of the body and possibly being more aware of the needs or even able to direct their action to an irritation or seek something for a need"*
- *"They know which body part they are aiming the action at"*

Theme 2: Learned non-use develops
Substantiating codes: • Facilitation required for full body awareness • Would rather compensate to complete the task
Discussion: Participants indicated that as a result of this increased awareness of their abilities and limitations, these patients often disregard their hemiplegic side in an attempt to complete a task without struggling. They therefore use the unaffected limb in tasks, while not being aware or interested in the affected limb.
Participants' supporting quotations: • *"They will still have a bit of a neglect though"* • *"I think this is where learned non-use starts. They start to become aware that that side doesn't work."* • *"They compensate"*

4.7.5 Domain of relational contact with tools and materials

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of their relational contact with tools and materials?"

4.7.5.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with tools and materials" domain for the level of Self-Presentation:

Theme 1: Basic tools and materials
Substantiating codes: • Identifies familiar tools • Explores with the unaffected side

Discussion:

The participants of the focus groups indicated that patients on a level of Self-Presentation are able to use basic, familiar tools and materials if prompted to do so. They continue to be unable to initiate this contact independently. The quality of use of tools is generally better in the correct context, with familiar tools (i.e. exactly what they used at home), so that they are able to draw on the automatic, splinter skills from their premorbid functioning.

Participants' supporting quotations:

- *"I think they can start to identify familiar tools and attempt to use them appropriately"*
- *"…but this one they might try to explore and try to squeeze the toothpaste with their affected side"*
- *"Yes, basic stuff especially if you washed at home with a wash cloth and you use a sponge, they will not understand that"*

Theme 2: Aware but not compliant with the norms of handling

Substantiating codes:

- Poor quality of tool use (uses the wrong side of the hairbrush)

Discussion:

Despite patients on a level of Self-Presentation's engagement with basic, familiar tools, participants indicated that their quality of tool handling remains poor as these patients are unable to comply with the norms. They generally know the purpose of familiar tools but are unable to use the tool correctly, as seen by the first quotation in the block below.

Participants' supporting quotations:

- *"Sometimes they would use the wrong side of the brush"*
- *"Still poor quality of use"*
- *"They can't comply with the norms"*

4.7.6 Domain of relational contact with the social world

Question asked:

"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of their relational contact with the social world?"

4.7.6.1 Themes and codes identified

The following three themes and substantiating codes were identified to describe the "relational contact with the social world" domain for the level of Self-Presentation:

Theme 1: Egocentric
Substantiating codes: • Based on needs and wants
Discussion: When directly compared to the level of Self-Differentiation, participants concluded that these patients are now able to respond to others, although inconsistently. These interactions are short lived and egocentric, despite their engagement with others. It is often based on their personal needs and wants and interaction is related to their immediate environment.
Participants' supporting quotations: • *"Still egocentric"* • *"Ja, their current condition"* • *"Complete dependence to handle unfamiliar situations"*
Theme 2: Automatic speech
Substantiating codes: • Pleasantries • Not always reciprocal
Discussion: Patients on the level of Self-Presentation present with automatic speech or pleasantries, such as an appropriate response to "Hello". They are however not always able to reciprocate interactions, e.g. they will not ask how their family members are doing.
Participants' supporting quotations: • *"I would say the automatic greetings"* • *"…even if it is an aphasic, it will be like a head nod"*

Theme 3: Emerging intent to interact
Substantiating codes: • Aware of others • Unable to initiate interaction • Interacts with the therapist
Discussion: Participants indicated that patients on a level of Self-Presentation display an emergence of intent to interact, despite being unable to initiate this interaction. On this level, they start to recognise and develop a relationship with their consistent therapist, albeit a superficial, needs based one.
Participants' supporting quotations: • *"Intent starts to emerge"* • *"They start to recognise the key health care providers, family"* • *"They will now engage with you even if you are unfamiliar"*

4.7.7 Domain of control of anxiety

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of their control of anxiety?"

4.7.7.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "control of anxiety" domain for the level of Self-Presentation:

Theme 1: Emotionally labile, poor emotional control
Substantiating codes: • Exaggerated emotions
Discussion: It became evident from the information gathered in the focus groups that patients on a level of Self-Presentation present with exaggerated emotions, often displaying emotions in direct response to failure that they have experienced. They are unable to modulate their own emotions and often refuse therapy or end a session early out of frustration.

Participants' supporting quotations:

- *"Poor emotional control and low frustration tolerance"*
- *"If they don't get something right, they will just stop"*
- *"They are not able to regulate"*
- *"They may refuse therapy"*
- *"I feel like this would be the most emotional that they would be"*

Theme 2: Fearful, low self-esteem

Substantiating codes:

- Increased insight into fallouts
- Requires success

Discussion:

As mentioned previously, patients on a level of Self-Presentation present with an increased awareness of their abilities and limitations. This results in an increase in fearful behaviour and low self-esteem. Participants emphasised that patients on this level are acutely aware that they are not meeting the standards set by society. They also present with an increased awareness of their inability to perform tasks safely and are therefore often fearful of movement.

Participants' supporting quotations:

- *"…activities must be successful"*
- *"They are becoming more aware of their impairments and fallouts, so when you put them into that situation. For example, a patient that can't stand, you are not putting in a standing frame, you get that freak out panic because they knew they fell over the other day when they were sitting."*
- *"They are fragile"*

4.7.8 Domain of ability to show initiative and make an effort

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of their ability to show initiative and make an effort?"

4.7.8.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "ability to show initiative and make an effort" domain for the level of Self-Presentation:

Theme 1: Poor initiative
Substantiating codes: • Makes an effort • Unplanned • Dependent on others to follow a home exercise programme
Discussion: Despite patients' engagement in tasks, participants indicated that patients on a level of Self-Presentation are unable to initiate tasks independently. Once a task is initiated for them, they are able to make an effort to execute some steps of the task. A further example of their explorative action can be seen in their problem solving approach, which is a 'trial and error' approach, rather than a direct plan to solve a problem.
Participants' supporting quotations: • *"…you are making an effort but no plan"* • *"There is almost like a trial and error problem solving approach"* • *"…they don't have the ability to problem solve and fix it"* • *"They don't say, I want to brush my teeth. It is you that says, do you want to brush your teeth and they say, oh ok."*
Theme 2: Poor frustration tolerance, unable to sustain effort
Substantiating codes: • Low perseverance • Refuses therapy
Discussion: Patients on a level of Self-Presentation are able to make a physical and cognitive effect to participate in basic, familiar tasks. Despite this effort, they present with poor frustration tolerance and therefore easily give up on a task that they find too difficult. This has a direct impact on their ability to sustain an effort.

Participants' supporting quotations:

- *"They make a physical and cognitive effort to explore"*
- *"I think perseverance is quite low. They become so frustrated that they just stop."*
- *"Short lived"*

4.7.9 Performance area of personal management

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of personal management?"

4.7.9.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "personal management" performance area for the level of Self-Presentation:

Theme 1: Dependent, aware of norms

Substantiating codes:

- Actively involved in BADL's with prompting and set-up
- Poor quality (they may only fix one side of their hair or stop participating in the task before completion)

Discussion:

According to the participants, patients on a level of Self-Presentation are more aware of the need to participate in personal management tasks. Despite this awareness, they are unable to comply with the norms related to these needs. They therefore often present unkempt unless prompted, facilitated and supervised by others. They are however able to participate in personal management tasks with set-up and guidance.

Participants' supporting quotations:

- *"They are becoming more aware of the need to be clean"*
- *"Bu they are still dependent and require assistance"*
- *"You are focusing more on BADL's vs other domestic chores"*
- *"They are more aware of it when [you] prompt them slightly"*
- *"They can't do it themselves"*
- *"And the quality is still poor"*

Theme 2: Responds better to a routine that is managed for them
Substantiating codes: • Routine must be managed for them • Improved execution
Discussion: Due to patients on a level of Self-Presentation's willingness to participate and present themselves, they respond well to a routine that is set up and managed for them, according to the focus group participants. This set-up can be external initiation and therefore they are able to proceed with a few steps of execution independently with supervision (in a basic, familiar task).
Participants' supporting quotations: • *"I do feel like with more basic things they can do it with set-up and supervision"* • *"…they respond well to routines"* • *"We have to initiate the thing still, or the routine has to be managed by someone else"*

4.7.10 Performance area of social ability

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of social ability?"

4.7.10.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "social ability" performance area for the level of Self-Presentation:

Theme 1: One on one level
Substantiating codes: • Functions in parallel to others in a group
Discussion: Patients on the level of Self-Presentation are able to respond better in a smaller social situation, preferably with only one communication partner, as indicated by the participants of the focus groups. Due to their low self-esteem and inability to initiate interaction, they easily become isolated in larger group settings.

Participants' supporting quotations:

- *"…at this stage you are more on the parallel play, there is other people here and I must do the same as them"*
- *"…their social ability on a one on one level is ok, but in a group setting it will be very isolated"*

Theme 2: Dependent on others, poor compliance with social norms and cues

Substantiating codes:

- No intent to initiate interaction
- Can interact with facilitation
- Unable to differentiate behaviour between known and unknown

Discussion:

Patients on a level of Self-Presentation are dependent on others to initiate social interaction despite their desire to engage. As previously mentioned, they are aware of the norms set by society but unable to comply with these norms. They are also not compliant with social cues. Patients on a level of Self-Presentation might therefore act inappropriately in social situations, often being unable to differentiate their behaviour between known and unknown people.

Participants' supporting quotations:

- *"The content is not great"*
- *"They will attempt to engage in basic conversation, egocentric, maybe one word back and forth"*
- *"Still very egocentric"*
- *"Still inappropriate"*
- *"They don't pick up on social cues"*
- *"They may not differentiate their behaviour between known and unknown, they will be overfamiliar"*

4.7.11 Performance area of work ability

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of work ability?"

4.7.11.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "work ability" performance area for the level of Self-Presentation:

Theme 1: Sheltered employment
Substantiating codes: • Repetitive • Constant supervision • Demonstration
Discussion: Due to their partial task concept, patients on the level of Self-Presentation are able to engage in basic tasks that are completely supervised and possibly demonstrated step by step. The participants indicated that patients on a level of Self-Presentation can therefore work in a well-structured, sheltered employment setting, where low demands are placed on production.
Participants' supporting quotations: • *"That repetitive, over and over, same thing with a supervisor, constant supervisor"* • *"Dependent on functional prognosis"*

4.7.12 Performance area of constructive use of free time

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Self-Presentation would present like in terms of constructive use of free time?"

4.7.12.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "constructive use of free time" performance area for the level of Self-Presentation:

Theme 1: Passive
Substantiating codes: • Facilitated by others • Sleep

Discussion:
The participants were in agreement that due to patients on a level of Self-Presentation's inability to initiate tasks, they are unable to use their time constructively. This results in them passively sitting in the ward or at home, despite a leisure task being in their close vicinity. If someone else initiates contact with this task and provides guidance throughout in order to sustain effort, they are able to participate in leisure tasks.
Participants' supporting quotations: • *"It is very much facilitated"* • *"Ja so they need lots of set-up and they need a fair amount of step by step, no planning"* • *"Nothing, they lie there"* • *"I think sleep is underrated, how much neuro patients sleep"*

4.7.13 Discussion on the level of Self-Presentation

Data saturation was reached for the majority of domains and performance areas discussed for the level of Self-Presentation. The researcher however found that the data provided regarding the work ability of a patient on the level of Self-Presentation did not reach data saturation. For this reason, literature for the domain "Work ability" was consulted in order to substantiate the final themes and codes for this domain. Literature was used to substantiate the data received for the other domains and performance areas to ensure that it is in line with the VdTMoCA and recovery following an ABI.

The main Disorders of Consciousness include the comatose state, the vegetative state and the minimally conscious state.[54] These three states are discussed in the preceding two levels of Creative Ability (Tone and Self-Differentiation) and therefore do not correlate with any of the higher levels of Creative Ability. As a result, the data obtained from the focus group participants for the level of Self-Presentation is substantiated by the Rancho Los Amigos Scale,[78] the Glasgow Coma Scale[56] and Maslow's Hierarchy of Needs.[57] Lastly, the data is further substantiated by information provided by du Toit[8] in a number of papers that she presented on the VdTMoCA and information by de Witt[53] on the VdTMoCA.

Following on from the discussion in the section on Self-Differentiation (section 4.6), the next levels according to the Rancho Los Amigos Scale[78] are Level 5: “Confused – Inappropriate – Non-agitated” and Level 6: “Confused – Appropriate”. According to the data obtained from the focus group participants, these two levels of the Rancho Los Amigos Scale correlate well with the level of Self-Presentation in a patient following an ABI.

The characteristic of Level 5: “Confused – Inappropriate”, according to the Rancho Los Amigos Scale, are[55,78]:

- Alert, not agitated
- Not orientated to place, time or person
- Poor problem solving
- Poor handling of tools and materials
- Requires assistance and facilitation to interact with others, tools or tasks
- Able to perform basic, familiar tasks with set-up and cueing (such as eating or dressing)
- Able to communicate superficially and automatically with facilitation
- Maximum assistance required

The characteristics of Level 6: “Confused – Appropriate”, according to the Rancho Los Amigos Scale, are[55,78]:

- Inconsistent orientation to place, person and time
- Recognition of familiar and consistent staff members
- Emerging awareness of appropriate responses (norm awareness)
- Emerging awareness of the need to participate in basic need tasks
- Require set-up and facilitation to interact with people, tools or tasks
- Able to perform basic, familiar tasks with set-up and cueing
- Poor awareness of impairments and safety risks
- Moderate assistance required

Levels 5 and 6 of the Rancho Los Amigos Scale correlate well with the data produced by the participants in this study.[55] As can be seen, progression has occurred from the preceding levels, with an emerging intent to engage with a task or others, present on this level. Patients in this phase of recovery continue to require

assistance and set-up in order to participate. They do however present with carry-over of knowledge on how to perform basic, familiar tasks such as eating or dressing. Despite this improving function, the Rancho Los Amigos levels and the participants' description of the level of Self-Presentation, make it clear that these patients remains confused and dependent on others for self-care tasks.[78]

According to the Glasgow Coma Scale,[56] patients on a level of Self-Presentation present with a score of between 10 and 12, labelling the injury as "moderate". Patients on this level of GCS generally present with moderate impairments in cognition, physical ability and emotional and behavioural functioning.[56] This correlates with the focus group data regarding patients on a level of Self-Presentation, as they remain confused, unable to perform tasks independently, are emotionally labile and unable to comply with the norms set out by society.

Maslow's Hierarchy of Needs,[57] Stage 2: "Safety needs", includes the need for protection from the elements, freedom from fear, security and stability. Patients on this stage of Maslow's Hierarchy are no longer in a critical state of care and are therefore able to focus their attention on needs other than pure survival. During this stage, they require safety and protection.[57] This stage is therefore in line with the data provided for patients on a level of Self-Presentation, as on this level, the patients are exploring the ability of their bodies, without insight into their limitations. They are therefore unsafe to function independently and require constant supervision and assistance to avoid further injury. They are also not yet aware of others and the need to belong in society and therefore are not yet functioning on a higher needs level.[57]

In order to further substantiate the data obtained during the focus groups, information provided by du Toit[8] and de Witt,[53] on mental health care users and children and their presentation according to the VdTMoCA, is discussed below.

According to du Toit,[8] the mental health care user on this level of Creative Ability provides evidence of a desire to present the self, with explorative activity participation. Du Toit[8] emphasises that despite the patient's engagement in tasks, they have not yet progressed to a participative level. Mental health care users on this level present with a low self-esteem and are externally motivated to participate. On the level of Self-Presentation, for the first time, the patient presents with a response towards others, although unable to initiate the interaction.[8] In line with this response to others, du Toit indicates that patients on this level of Creative Ability are also able to develop patient-therapist relationships (superficially).[8]

According to de Witt,[53] activity participation on this level is influenced by a number of factors, including poor concrete and abstract decision making, poor self-concept, an inability to work at an acceptable rate, impulsivity, poor quality of product or performance, an inability to problem solve to improve performance and an inability to delay gratification. De Witt[53] further states that patients on this level of Creative Ability present with partial task concept, being more interested in the process of participation than the quality of the end product.

Du Toit[8] and de Witt[53] both indicate that the personal management of patients on a level of Self-Presentation has improved, although the quality is still poor and they require set-up and facilitation to participate. They do however display an increased awareness of the need to participate in self-care tasks.[8,53]

According to du Toit[8] and de Witt,[53] patients on a level of Self-Presentation are aware of others and present with an intent to interact. They are however unable to initiate interaction. Their interaction is also egocentric.[8,53]

In terms of their work ability, du Toit[8] and de Witt[53] state that patients on a level of Self-Presentation are able to work in a protected or sheltered work environment that requires a low level of skill, is undemanding and highly supervised. In a paper that du Toit[8] presented in 1974 on the work capacity of patients on the different levels of Creative Ability, she concluded that patients on a level of Self-Presentation's employment potential includes working in a sheltered workshop, with a production of less than fifty percent (50%).

Patients on this level are aware of leisure tasks and will participate with facilitation. Their poor ability to show initiative is also evident in their leisure participation, as they are unable to independently participate in such tasks.[8,53]

As can be seen by the above information provided by du Toit[8] and de Witt[53] on the level of Self-Presentation in mental health care users, the data provided by the participants of this study on the presentation of patients following an ABI, is in line with the VdTMoCA. The data regarding the work ability of patients on a level of Self-Presentation will remain in line with the information provided by du Toit[8] and therefore be included in the outcome measure as indicated in the discussion above.

4.7.14 Conclusion on the level of Self-Presentation

For the level of Self-Presentation, a patient's focus is on presenting their new self to others and exploring the abilities of their new body. Self-Presentation is the first level where a patient purposefully engages in a task. Despite this engagement, patients on this level present with partial task concept, with emphasis placed on the process of task participation rather than on the end product. They present with poor initiative, low frustration tolerance and a low self-esteem. Patients on a level of Self-Presentation present with an increased awareness of their physical abilities and limitations and apply compensatory strategies taught to them. Due to the patients' emphasis on the process of task participation, patients on this level often tend to present with learned non-use of their affected limb. In terms of personal management, patients on this level are able to actively participate in basic, familiar tasks with set-up and supervision. They are able to work in a sheltered or protected work environment, provided it is well structured, repetitive work with constant supervision. The data provided by the participants of this study is substantiated by level 5 and 6 of the Rancho Los Amigos Scale,[78] the Glasgow Coma Scale[56] and Maslow's Hierarchy of Needs[57] as well as by information provided by du Toit[8] and de Witt[53] on the VdTMoCA in mental health care users and children.

4.8 Creative Ability level of Passive Participation

The fourth level of Creative Ability is the first of the participation levels, namely "Passive Participation".[8] On a level of Passive Participation, a patient's motivation is aimed at establishing the rules and acceptable norms. They are goal directed and unable to initiate tasks independently. The patient is able to sustain interest in an activity that is structured and initiated by others. Their emotions are more refined.[8]

Table 4.7 below provides a summary of the themes and substantiating codes derived from the focus group data for the level of Passive Participation.

The level of Passive Participation is divided into the domains and performance areas described in Section 4.3. The participants were asked to discuss each domain and performance area according to each level of Creative Ability.

The results obtained from the focus groups for these domains and performance areas for the level of Passive Participation are presented as follows:

1. Question asked/prompt
2. Themes and codes identified
3. Discussion of the participants' responses regarding the specific domain
4. Supporting quotations provided by the participants

Finally, the level of Passive Participation is concluded with a discussion of the focus group findings related to literature available on the VdTMoCA and ABI's.

Table 4.7: Themes and substantiating codes for Passive Participation

PASSIVE PARTICIPATION		
Domains	**Themes**	**Substantiating codes**
Motivation	1. Directed to the attainment of skills and establishing norms	• Motivated to meet norms (physically, socially, task)
	2. Externally motivated	• Motivated to meet norms and please others
Action	1. Skills or product centred, therapist directed, safe	• Action is focused on skill • Passive, requires prompting
	2. 2-4 steps with global instructions, 5-7 steps with step by step instructions (including preparatory movements)	
Quality of product and task concept	1. Consolidated task concept for basic tasks	• Good understanding of BADL's (improved execution and completion) • Poor initiative shown
	2. Requires facilitation for initiation. Can continue with execution and completion	• Unable to problem solve to improve performance
	3. Aware of norms, not compliant. Concrete evaluation	• Poor quality • Unable to problem solve to improve performance
Relational contact with the body	1. Aware of affected limb and theory regarding care	• Unable to initiate fixing the limbs positioning
	2. Purposeful, safe use of body with compensatory techniques	• Focused on completing the task
Relational contact with tools and materials	1. Aware of the purpose of tools	• Use tools for their intended purpose
	2. Able to use assistive devices with guidance	
Relational contact with the social world	1. Superficial, concrete, current	• Unable to reciprocate
	2. Interacts with facilitation, aware of the norms	
	3. Passive participant in a support group	
Control of anxiety	1. Able to name and recognise concrete emotions	
	2. Depression	• Increased awareness (social norms and physical limitations)
Ability to show initiative and make an effort	1. Able to initiate and make an effort to fulfil a need with set-up	• BADL's • Effort is more sustained • Unable to follow home exercise programme independently
	2. Unable to problem solve within a task	

4.8.1 Domain of motivation

Question asked: "Let's talk about the fourth level of the outcome measure – Passive Participation. Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of their motivation?"

4.8.1.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "motivation" domain for the level of Passive Participation:

Theme 1: Directed to the attainment of skills and establishing rules and norms
Substantiating codes: • Motivated to meet the norms (physically, socially and of the task)
Discussion: The research participants indicated that on a level of Passive Participation, patients are motivated to attain skills and establish the rules and norms. On this level, the patient is aware of the physical, social and task-specific norms set by society and therefore motivated to attain the skills required to meet these norms. Patients are however unable to independently comply with these norms and therefore require direct assistance from others during task set-up and participation.
Participants' supporting quotations: • *"…it is more doing what is in front of you and what they rest of the group is doing"* • *"I think you would not expect norm compliancy, but you would encourage it"* • *"Their motivation is aimed towards improving their physical health"*
Theme 2: Externally motivated
Substantiating codes: • Motivated to meet the norms and please others
Discussion: On the level of Passive Participation, patients are externally motivated to meet the norms as mentioned above, as well as motivated to please others. This can be seen in their low self-esteem and dependence on others during task participation. They are unable to initiate tasks independently and show little motivation to perform tasks not set-up for them by others.

Participants' supporting quotations:

- *"I think that they are at a level where they are aiming to succeed, but they want to please"*
- *"No intrinsic motivation"*
- *"They also need an external driver"*
- *"I almost feel like sometimes they want to make me happy"*

4.8.2 Domain of action

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of their action?"

4.8.2.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "action" domain for the level of Passive Participation:

Theme 1: Skill or product centred, therapist directed, safe

Substantiating codes:

- Action is focused on attaining skill
- Able to complete basic tasks independently with set-up
- Passive
- Requires prompting, cues and supervision

Discussion:

The participants emphasised that patients on a level of Passive Participation's action is skill or product centred (much like their motivation). These patients direct their actions towards attaining previous skills and abilities, although they are unable to do this independently. On this level, patients are still dependent on a therapist, family member or the nursing staff to set-up personal management tasks on their behalf and possibly even provide assistance during execution. Despite this need for others intervention; these patients are generally safe to be left alone during simple, familiar tasks, as they will passively follow instructions with no further action.

Participants' supporting quotations:

- *"Ja, but still needing quite a lot of facilitation and cueing"*
- *"They are safe in the ward"*
- *"Action is not product centred, I would say more skill centred"*
- *"Their action is skill centred and focused towards the attainment of previous skills and abilities"*

Theme 2: 2-4 steps with global instructions

5-7 steps with step by step instructions (including preparatory movements)

Discussion:

Engagement in tasks continues to develop on the level of Passive Participation. The participants indicated that these patients are able to execute two to four steps of a task independently once the task has been set-up and they have been prompted to participate. If the patient is given step by step instructions and more guidance in the task, they will be able to perform five to seven steps of the task, with preparatory movements included in the number of steps (i.e. maintain an upright seated position).

Participants' supporting quotations:

- *"I think we are looking more at a 2-4 step task, still with facilitation and cueing"*
- *"So this is 3-4 steps"*

4.8.3 Domain of quality of product or performance and task concept

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of their quality of product or performance and task concept?"

4.8.3.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "quality of product or performance and task concept" domain for the level of Passive Participation:

Theme 1: Consolidated task concept for basic tasks. Patient requires facilitation for initiation. They are able to continue with execution and completion.

Substantiating codes:

- Good understanding of BADL's
- Unable to problem solve to improve performance

Discussion:

On the level of Passive Participation, patients present with consolidated task concept according to the research participants. They are able to actively participate in all phases of task concept (namely initiation, execution and completion) with relative independence. This independence is seen mostly in basic, familiar tasks such as personal management, although they still require set-up and facilitation to participate. Patients on this level are more concerned with the process of participation than the quality of the end product.

Participants' supporting quotations:

- *"…they are more concerned with the actual process of the task than the end product"*
- *"Yes, total task concept, so they go through all the phases of task concept"*
- *"They know what dressing is, they know what washing is"*
- *"If you show them something, they will do it"*
- *"So we are looking at your basic grooming, basic self-care tasks can be carried out with facilitation of the initiation and structured, but we are not looking at your more complex tasks at all"*

Theme 2: Aware of the norms but not compliant. Concrete evaluation of end product or performance

Substantiating codes:

- Product of fair quality (establishing norms, but not compliant)
- More interested in task participation than completion

Discussion:

The participants emphasised that despite the patient's awareness of all the phases of task concept, patients on a level of Passive Participation find it difficult to appropriately evaluate their end product. This could be due to their focus being on the process of participation rather than the end product. A patient of a level of Passive Participation's product is usually of a poor quality due to their inability to comply with the norms set by society. They are unable to problem solve in order to improve their performance or product.

Participants' supporting quotations:

- *"I think they might just have difficulties realistically evaluating the end product"*
- *"Some recognition of error but unable to self-correct"*
- *"The product is fair quality. Or their movement. I think if they do move their hemi arm, it is not norm compliant."*

4.8.4 Domain of relational contact with the body

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of their relational contact with the body?"

4.8.4.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with the body" domain for the level of Passive Participation:

Theme 1: Aware of the affected limb and theory regarding care

Substantiating codes:

- Unable to initiate fixing of the affected limb's positioning

Discussion:

Participants indicated that on a level of Passive Participation, patients are able to carry over information repeatedly given to them. They present with an increased awareness of their affected limb and are aware and able to repeat theory regarding the appropriate care needed for this limb. Due to their decreased initiative, they are however unable to independently correct the position of their upper limb without prompting.

Participants' supporting quotations:

- *"I think they still need reminding of their arm"*
- *"I think they often repeat things that they have heard, but on a theoretic level but often don't act on it"*
- *"They are aware of their weakness"*

Theme 2: If facilitated, purposeful, safe use of the body with compensatory techniques

Substantiating codes:

- Focused on completing the task according to the norms

Discussion:

Patients on a level of Passive Participation present with good body awareness (of the affected and unaffected limbs) according to the participants. As mentioned previously, they are more interested in the process of participation than the quality and therefore often tend to perform compensatory movements in an attempt to complete a task, which results in them ignoring the affected limb. Despite these compensatory movements, they are able to use their body purposefully and safely to complete tasks if facilitated to do so.

Participants' supporting quotations:

- *"Purposeful, goal directed"*
- *"Compensatory techniques are following with more regularity"*
- *"They know left and right, up and down, spatial awareness, body awareness is in place"*
- *"I think they are more focused on getting the task completed, so if you say let's use the weaker arm more, they will say no, I just want to get it done, it is the easiest way"*

4.8.5 Domain of relational contact with tools and materials

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of their relational contact with tools and materials?"

4.8.5.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with tools and materials" domain for the level of Passive Participation:

Theme 1: Aware of the purpose of tools
Substantiating codes: • Use tools for their intended purpose
Discussion: Participants emphasised that patients on a level of Passive Participation are aware of the purpose of tools and able to use basic, familiar tools independently once this interaction has been set-up for them. They do not require physical assistance for the use of basic tools, as their task concept is consolidated and therefore they are able to execute basic tasks independently.
Participants' supporting quotations: • *"I think now they are using things for the right purpose"* • *"They can eat, they can wash, they know what a toothbrush is"*
Theme 2: Able to use assistive devices with guidance
Discussion: Patients on a level of Passive Participation require assistance and demonstration for the use of novel tools. Despite this assistance, they are able to execute tasks with novel tools with fair quality of execution. They are aware of the norms of tools, although not always compliant and therefore present with occasional inappropriate use of novel tools if guidance is not given. They are aware of the safety aspects of tools.
Participants' supporting quotations: • *"If you give them new stuff and tell them, they will be able to use it with feedback"* • *"They are aware of the norms of tools, if you give them something new and unknown but it has a sharp end, they will be able to identify the sharp end"*

4.8.6 Domain of relational contact with the social world

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of their relational contact with the social world?"

4.8.6.1 Themes and codes identified

The following three themes and substantiating codes were identified to describe the "relational contact with the social world" domain for the level of Passive Participation:

Theme 1: Superficial, concrete, current

Substantiating codes:

- Unable to reciprocate
- Related to their current situation

Discussion:

Due to their continued egocentricity, patients on a level of Passive Participation are unable to reciprocate conversations. Their conversations are superficial, concrete and related to current events and their personal needs and wants. Despite this, they are able to hold a basic conversation if the topics are directed by their communication partner.

Participants' supporting quotations:

- *"They can have like basic conversations of their immediate environment"*
- *"Once they do that communication, it is very concrete, in the now"*

Theme 2: Interacts with facilitation by others

Substantiating codes:

- Acts as a follower
- Able to have a basic conversation
- They will be a passive participant in a support group

Discussion:

Participants indicated that on this level, patients present with an increased awareness of others and are attempting to communicate with set-up. If placed in a group, a patient on a level of Passive Participation will interact if facilitated to and generally act as a follower within the group. They are unable to independently handle unfamiliar situations, although with facilitation, can be involved in the problem solving process of that situation.

Participants' supporting quotations:

- *"Ja definitely, the other communication partner has to kind of force it"*
- *"I think now they will try to communicate. Communicates, acts as a follower in a variety of situations."*
- *"Assist in a unfamiliar situation"*

Theme 3: Aware of the social norms but not compliant

Substantiating codes:

- Not compliant with the norms

Discussion:

According to the information gathered in the focus groups, patients on a level of Passive Participation are aware of social norms but not independently compliant. For this reason, as mentioned above, they act as followers in social situations as they are motivated to meet the norms. They therefore get their social cues from others around them in order to interact appropriately in social situations. Without these cues, patients on this level will merely sit passively.

Participants' supporting quotations:

- *"They are aware but they are not going to address it"*
- *"I think when it comes to social norms, they still take their [cueings] very much from those around them"*

4.8.7 Domain of control of anxiety

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of their control of anxiety?"

4.8.7.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "control of anxiety" domain for the level of Passive Participation:

Theme 1: Names and recognises concrete emotions

Discussion:

Participants emphasised that patients on a level of Passive Participation are able to name and recognise concrete emotions. This is due to their increased awareness of their surroundings, as well as their norm awareness. In a controlled, familiar environment, these patients are able to handle their emotions well without inappropriate outbursts. Their frustration tolerance has improved to a point where they are able to persist through a problem without allowing emotions to impact their functioning.

Participants' supporting quotations:

- *"The control will be much better"*
- *"Appropriate communication and response to things"*
- *"They can put a name to an emotion"*
- *"I think they can control their basic everyday emotions"*

Theme 2: Depression

Substantiating codes:

- Increased awareness of their social and physical limitations and their non-compliance

Discussion:

As a result of their increased insight into their physical limitations and inability to meet the norms, patients on a level of Passive Participation often present with low mood or depression.

Participants' supporting quotations:

- *"More insight into their limitations"*
- *"I think that this level, they still have a big awareness of what they can and can't do and so that might make them feel depressed"*
- *"I think a lot of the time they fall into a depression here"*

4.8.8 Domain of ability to show initiative and make an effort

Question asked:

"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of their ability to show initiative and make an effort?"

4.8.8.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "ability to show initiative and make an effort" domain for the level of Passive Participation:

Theme 1: Able to initiate and make an effort to fulfil a need with set-up
Substantiating codes: • BADL's • Effort is more sustained • Unable to follow a home exercise programme independently • Improved execution in a routine
Discussion: The participants emphasised that as a result of their consolidated task concept, patients on a level of Passive Participation are able to initiate basic, familiar tasks with set-up. Once set-up with a task, these patients are able to continue independently until completion. Due to poor abstract reasoning and problem solving, the quality of their product or performance is fair, but they are able to sustain their effort for task completion. Due to their need for set-up and facilitation to initiate tasks, they are unable to follow a home programme given to them, therefore requiring someone else to set-up and facilitate this programme.
Participants' supporting quotations: • *"They are able to initiate a familiar task in a familiar environment"* • *"And they make an effort but the therapist is their cheerleader"* • *"I think the initiative comes from others"*
Theme 2: Unable to problem solve within a task
Discussion: The participants emphasised that due to the patient's decreased abstract reasoning and inability to evaluate their own performance or product, patients on a level of Passive Participation are unable to problem solve within a task (to improve performance or to overcome obstacles).

Participants' supporting quotations:

- *"Ja, I think here it is still not good, probably not a good plan"*
- *"They are aware that there is a problem, but they still can't solve it without assistance"*

4.8.9 Performance area of personal management

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of personal management?"

4.8.9.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "personal management" performance area for the level of Passive Participation:

Theme 1: Participates independently in BADL's within a routine, with set-up

Substantiating codes:

- Poor quality
- Aware of the norms but not compliant

Discussion:

As mentioned previously, patients on a level of Passive Participation are able to independently complete basic, familiar tasks with set-up. They are unable to live independently due to their inability to initiate tasks without set-up. Patients on a level of Passive Participation participate well within a routine that is set-up and guided by someone else. Due to their inability to comply with norms, the quality of their performance is fair.

Participants' supporting quotations:

- *"I think they do better with a set daily routine and someone to go through it with them"*
- *"Here they can sustain the effort to the end of the task, they just have difficulty with aspects of the task"*
- *"I think they quality is just not there"*

Theme 2: Starting simple IADL tasks with prompting and set-up

Substantiating codes:

- Better within a routine

Discussion:

Patients on a level of Passive Participation are able to act as followers in a variety of situations according to the information gathered in the focus groups. This includes participation in domestic tasks. As a result, they are able to do simple household tasks with set-up and facilitation. This includes washing dishes with someone else or assisting with food making. Again, the quality of their product or performance may be fair but with guidance, they can participate and complete such domestic tasks.

Participants' supporting quotations:

- *"…they could start to engage on a domestic level"*
- *"They are starting to participate more in IADL tasks"*

4.8.10 Performance area of social ability

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of social ability?"

4.8.10.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "social ability" performance area for the level of Passive Participation:

Theme 1: Able to interact with set-up

Substantiating codes:

- Starts to make friends in the ward
- Able to follow basic instructions

Discussion:

As with all the above mentioned domains and performance areas, the participants indicated that patients on a level of Passive Participation require set-up in order to participate in social situations. They present with an increased awareness of others around them and therefore start to make friends in the ward, with facilitation. They can often be seen as "cold" due to their inability to initiate interactions independently.

Participants' supporting quotations:

- *"…having a basic conversation"*
- *"Setting them up for it"*
- *"They won't initiate social interaction"*
- *"They will have friends. They may just not decide what activity to do as a friend but they will participate."*
- *"I think it is still that superficial, concrete conversation"*

Theme 2: Can be included in groups

Substantiating codes:

- Will participate passively
- Task orientated groups

Discussion:

Patients on a level of Passive Participation act as followers and can therefore be included in group settings, as they will participate passively and attempt to follow the rules of the group by following the lead of others. Task orientated groups would provide these patients with an environment to participate within a group, while not placing too much pressure on them to actively interact with others. They perform better in smaller groups, where less pressure is placed on complying with the norms.

Participants' supporting quotations:

- *"2-3 conversation partners"*
- *"You can put them in a group. They will say their name and listen to everyone."*
- *"I think they can participate in small group environments, especially if it is task orientated"*

4.8.11 Performance area of work ability

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of work ability?"

4.8.11.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "work ability" performance area for the level of Passive Participation:

Theme 1: Sheltered employment

Substantiating codes:

- Routine
- Repetitive
- Will follow job description
- Supervision is required

Discussion:

The participants concluded that a suitable work environment for a patient on the level of Passive Participation would be sheltered employment. Due to their consolidated task concept, they are able to understand and complete basic tasks that require repetition and are within a routine. They are unable to handle unfamiliar situations where they would be required to problem solve and therefore require supervision throughout the day. They can evaluate their end product against concrete examples; although they would not be able to problem solve to improve their performance. Work within a production line would be appropriate for such a patient.

Participants' supporting quotations:

- *"I think they can initiate tasks with set-up, especially if they have done it and they are comfortable with it"*
- *"They might not be able to structure or organise themselves in a work task"*
- *"Like an assembly line where they do one thing"*
- *"…they don't deal well with things that need problem solving"*
- *"There isn't a drive to improve where they are"*
- *"Some repetition but not all of it would have to be. The task would have to be repetitive but the components of the task wouldn't have to be."*
- *"So sheltered where you are working under reasonable accommodations"*

4.8.12 Performance area of constructive use of free time

Question asked:

"Is there anything that stands out for you in terms of what a neurological patient on a level of Passive Participation would present like in terms of constructive use of free time?"

4.8.12.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "constructive use of free time" performance area for the level of Passive Participation:

Theme 1: Passive
Substantiating codes: • Requires prompting to participate in tasks • Will sit passively with the task next to them • TV
Discussion: As previously mentioned, patients on a level of Passive Participation are unable to initiate tasks independently. They will however participate appropriately if the task is initiated for them. The same goes for the use of their free time. These patients tend to sit passively, despite leisure tasks being within their reach. Once facilitated to participate, they will happily comply and interact or complete the task.
Participants' supporting quotations: • *"Very structured"* • *"Initiated to an extent. To me, these people just sit. They have a book and everything there, but you have to prompt them."* • *"A lot of passive tasks"* • *"Sitting with family listening to them talk"* • *"Sedentary, something that does not require a lot of creativity or variety"*

4.8.13 Discussion on the level of Passive Participation

During the analysis of the data obtained in the focus groups, the researcher determined that data saturation was reached for all the domains and performance areas. Literature was used to substantiate the data collected in the focus groups and further validate the data to be included in the measure.

The data obtained from the focus group participants for the level of Passive Participation is substantiated by the Rancho Los Amigos Scale,[78] the Glasgow Coma Scale[56] and Maslow's Hierarchy of Needs.[57] The data is further substantiated by information provided by du Toit[8] in a number of papers that she presented on the VdTMoCA and information by de Witt[53] on the VdTMoCA.

Following on from the discussion in the section on Self-Presentation, the next level according to the Rancho Los Amigos Scale is, Level 7: “Automatic – Appropriate”.[78] According to the data obtained from the focus group participants, this level of the Rancho Los Amigos Scale correlates well with the level of Passive Participation in a patient following an ABI.

According to the Rancho Los Amigos scale, Level 7: “Automatic – Appropriate”, is characterised by the following[55,78]:

- Consistent orientation to place, person and time within familiar environments
- Completion of highly familiar tasks in an appropriate environment with minimal assistance
- Improved carry over of newly learnt information
- Superficial awareness of his or her physical fallouts and the implication thereof
- Improved functioning within a routine
- Poor abstract reasoning, difficulty finding solutions to problems
- Superficial social interactions
- Non-compliance with the norms set by society
- Participation in social and leisure tasks with facilitation and set-up
- Minimal assistance for routine, familiar tasks

Level 7 of the Rancho Los Amigos Scale correlates well with the data produced by the participants in this study. Being the first of the “participation” levels according to the VdTMoCA, patients on a level of Passive Participation now purposefully engage in tasks.[78] It is however evident that this engagement is dependent on initiation and set-up from someone else, as these patients continue to lack the internal motivation to initiate interaction independently. They display improved independence in basic, familiar tasks within a routine, in an appropriate environment. Tying in with their lack of initiative, it is evident from the data obtained and level 7 of the Rancho Los Amigos Scale that these patients present with poor abstract reasoning and problem solving. They are aware of the norms set by society, but not compliant which often results in patients on a level of Passive Participation presenting with low self-esteem.[78]

According to the Glasgow Coma Scale,[56] patients on a level of Passive Participation present with a score of between 13 and 15, labelling the injury as “mild”. Patients on this level of GCS generally present with noticeable neurological impairments that may or may not be permanent. They are fully conscious and able to perform motor responses consistently on command (with the unaffected side). They may remain slightly confused at times, but they are able to communicate effectively.[56] This correlates with the data obtained regarding patients on a level of Passive Participation, as they are fully conscious and motivated to establish the rules and norms of society. They are however still unsafe to be left alone due to confusion and decreased initiation, as seen in their GCS scores as well.[56]

Maslow’s Hierarchy of Needs,[57] Stage 3: “Love and belongingness needs”, is the need for interpersonal relationships and belongingness. This includes being affiliated with a group and friendship.[57] Despite patients on a level of Passive Participation being unable to initiate interaction independently, they have a desire to be accepted. This is seen in their motivation being directed at establishing rules and norms and their resultant low self-esteem and depression cause by not complying with these norms.

In order to further substantiate the data obtained during the focus groups, information provided by du Toit[8] and de Witt,[53] on psychiatric patients and their presentation according to the VdTMoCA, is discussed below.

According to du Toit,[8] psychiatric patients on this level present with motivation that is directed towards the establishing of rules and norms that are acceptable to society. The action that is associated with this motivation is experimental in nature. Despite this experimentation with their behaviour, the patient is passive and can be seen as a follower. Their experimentation is in response to behaviour that they have observed in others and they are therefore unable to independently initiate this action without someone else. Du Toit[8] states that these patients present with more refined emotions and an ability to control their emotions in familiar settings. The mental health care user on a level of Passive Participation is aware of the norms set by society, although they are not compliant with these norms. Patients on this level are able to sustain their effort over a longer period of time, provided that the task provides motivation for

them. They are also unable to problem solve in order to improve the quality of their product.[8]

De Witt[53] defines the presentation of mental health care users on the Passive Participation level in the four performance areas. In terms of personal management, these patients are able to complete basic, familiar self-care tasks within a routine. They are also able to participate in less familiar tasks such as domestic tasks with set-up and prompting from another person. De Witt[53] specifies that as a result of their poor pre-vocational skills, these patients present with poor quality of task performance.

In terms of their social ability, de Witt[53] states that mental health care users on a level of Passive Participation have a desire to be included in groups and for acceptance (much like stage 3 of Maslow's Hierarchy of Needs[57]). Despite this desire, large group settings can provoke anxiety as they do not like to be singled out. Patients on a level of Passive Participation are able to form superficial relationships, initiated by others. Despite being able to hold a basic conversation, the topic of their conversations remains egocentric and superficial.[8,53]

According to de Witt[53] and du Toit,[8] mental health care users on a level of Passive Participation are able to work within the sheltered labour market, or the open labour market (provided the job places little emphasis on quality and rate of performance). Their consolidated task concept assists in the work place by allowing the patient to initiate and complete a task within a routine with minimal assistance. Despite their need for less rigorous supervision, they do still require the steps and sequence of the task be confirmed.[8,53]

Mental health care users on a level of Passive Participation tend to use their free time unproductively if not facilitated to participate in a task. Despite this passivity, these patients are able to actively participate and enjoy leisure tasks if facilitated to interact.[53]

As can be seen by the information provided by du Toit[8] and de Witt[53] on the level of Passive Participation in mental health care users, the data provided by the

participants of this study on the presentation of patients following an ABI, is in line with the VdTMoCA.[8]

4.8.14 Conclusion on the level of Passive Participation

For the level of Passive Participation, the patients focus is on establishing the rules and norms set by society. Passive Participation is the first of the levels of "participation". Patients on this level present with consolidated task concept. Despite the consolidation of task concept, they present with poor initiation of tasks and therefore require a routine or set-up in order to participate (on a functional, social or vocational level). Patients on a level of Passive Participation also present with poor problem solving which results in poor quality of product or performance. As a result of their action aimed at establishing skills in order to comply with the norms, this inability to produce a product of good quality results in the patients on this level often presenting with poor self-esteem and possibly even depression. The lack of initiative that is so evident in this phase can also be seen in the patient's handling of their body – they are able to learn the principles behind appropriate ways of caring for their hemiplegic upper limb, although they are unable to implement these principles independently. In terms of personal management, they are able to complete tasks independently within a routine or with set-up. Domestic tasks can be performed, with poor quality, with set-up or within a routine. In terms of work, patients on a level of Passive Participation can be employed in the sheltered or open labour market, provided little to no emphasis is placed on rate and quality of performance. The data provided by the participants of this study is substantiated by level 7 of the Rancho Los Amigos Scale,[55] the Glasgow Coma Scale,[56] Maslow's Hierarchy of Needs[57] and by information provided by du Toit[8] and de Witt[53] on the VdTMoCA in psychiatry.

4.9 Creative Ability level of Imitative Participation

Patients on the fifth level of Creative Ability – “Imitative Participation”, are predominantly focused on complying with the norms set by society.[8] This is the first stage where individuality is evident, although this requires a group or someone else who the patient can imitate. Their motivation is product centred.[8] They are unable to show initiative in novel situations, but can initiate tasks within a routine or structured environment. Patients on this level are reluctant to compete and compare with others and are stressed by the unknown (where the norm is unclear).[8]

Table 4.8 below provides a summary of the themes and substantiating codes derived from the focus group data for the level of Imitative Participation.

The level of Imitative Participation is divided into the domains and performance areas described in Section 4.3. The participants were asked to discuss each domain and performance area according to each level of Creative Ability. The results obtained from the focus groups for these domains and performance areas for the level of Imitative Participation are presented as follows:

1. Question asked/prompt
2. Themes and codes identified
3. Discussion of the participants’ responses regarding the specific domain
4. Supporting quotations provided by the participants

Finally, the level of Imitative Participation is concluded with a discussion of the focus group findings related to literature available on the VdTMoCA and ABI’s.

Table 4.8: Themes and substantiating codes for Imitative Participation

IMTIATIVE PARTICIPATION		
Domains	**Themes**	**Substantiating codes**
Motivation	1. Intrinsically motivated to achieve something	• Money, belonging, norm movement, what was lost
Action	1. Imitative, norm directed	• Imitate norms and premorbid functioning
	2. 7-10 steps	• Good task concept
Quality of product and task concept	1. Full task concept	• Independent with a routine • Can participate in abstract tasks with supervision
	2. Product or performance of good quality. Able to evaluate end product	• Good movement • Look for norms as comparison
Relational contact with the body	1. Acceptance of new body image, still working for recovery	• Realistic perception of body • Aware of limitations and abilities • Able to compensate for limitations
	2. Able to care for the hemiplegic side	• Correcting the limbs positioning • Performing stretches
Relational contact with tools and materials	1. Appropriate use of tools including assistive devices	
	2. Tools and materials used for their intended purpose	• Little abstract thinking to change the purpose of tools to suit their needs
Relational contact with the social world	1. Norm compliant, aware of social cues	• Socially appropriate
	2. Able to hand a variety of situations	• Imitates norm compliant individuals in unfamiliar situations
	3. Rely on others to initiate interaction	• Will interact with friends and family within a routine
	4. Involved in support groups	
Control of anxiety	1. Able to express, control and display a variety of emotions	• Can apply coping mechanisms • Psycho-social/emotional treatment can start
	2. Anxious in unfamiliar situations	• Unable to problem solve in unfamiliar situations • Anxiety may impair function in an unfamiliar situation
Ability to show initiative and make an effort	1. Able to initiate and put maximum effort into meaningful tasks	• No extra effort given (just meets norms) • Effort is sustained until task completion • Follows home exercise programme
	2. Able to problem solve concrete problems	
	3. Unable to problem solve in unknown situations	

4.9.1 Domain of motivation

Question asked:
"Let's talk about the fifth level of the outcome measure – Imitative Participation. Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of their motivation?"

4.9.1.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the domain of "motivation" for the level of Imitative Participation:

Theme 1: Intrinsically motivated to achieve something

Substantiating codes:

- Money, belonging, normal movement, what they lost

Discussion:

The participants emphasised that the development of intrinsic motivation is first seen on the level of Imitative Participation. These patients are motivated to achieve something personal, be it finances, social belonging, normal movement or the life that they feel they lost with the injury. Their motivation extends further than survival and approval from others as seen in the preceding levels, as they imitate their premorbid self and others around them in an attempt to achieve a predetermined goal (as mentioned above).

Participants' supporting quotations:

- *"If they are motivated by money, they will direct their motivation to that"*
- *"There is an intrinsic motivation here to actually participate because they want something"*
- *"I would say directed to normal skill"*
- *"Normal quality of movement and level of functioning and cognition"*
- *"It is that part of being again"*

4.9.2 Domain of action

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of their action?"

4.9.2.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the domain of “action” for the level of Imitative Participation:

Theme 1: Imitative, norm directed
Substantiating codes: • Imitate norms and premorbid function • Imitate normal function and normal movement
Discussion: As suggested in the name, the action of a patient on a level of Imitative Participation is imitative in nature. The participants indicated that this imitation stretches further than imitating those around them. Following an ABI, patients on this level tend to imitate their premorbid self and functioning in an attempt to regain this function. They can also be seen imitating what high-functioning individuals around them are doing, in an attempt to be “normal” again and to comply with the norms set by society. Without this imitative action, they find it difficult to comply with these norms.
Participants’ supporting quotations: • *“I think being normal again, like doing what other people do”* • *“Imitating your previous self”* • *“I think it is very norm directed”* • *“…they want to imitate previous self, imitate normal movement, previous roles and occupations”*
Theme 2: 7-10 steps
Substantiating codes: • Good task concept in familiar and unfamiliar tasks within an established routine
Discussion: The participants concluded that on the level of Imitative Participation, with improved task concept and norm compliance, these patients can perform between seven to ten steps of a task independently. They do however initially require set-up or structuring in order to participate, but following that initial intervention, they are independent in basic and some more advance tasks.

Participants' supporting quotations:

- *"I think at the top of imitative, we can do 7-10 steps"*
- *"They would be pretty good at ADL's"*

4.9.3 Domain of quality of product or performance and task concept

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of their quality of product or performance and task concept?"

4.9.3.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "quality of product or performance and task concept" domain for the level of Imitative Participation:

Theme 1: Full task concept

Substantiating codes:

- Independent in ADL's with an established routine
- Unable to set up their own routine
- Able to imitate a programme
- Participates in less familiar tasks within a routine

Discussion:

The participants of the focus groups indicated that patients on a level of Imitative Participation have full task concept. They are able to follow a routine independently. This routine needs to be structured for them. Patients on a level of Imitative Participation are safe to be left at home for periods of time with a well-defined routine. Due to their fully developed task concept, they are able to participate in abstract tasks with supervision, where they can imitate the norms.

Participants' supporting quotations:

- *"You could leave them at home alone and go somewhere and they would be safe"*
- *"…definitely have good task concepts"*
- *"They can imitate the programme"*

Theme 2: Product or performance of good quality. Able to evaluate end product according to the norm
Substantiating codes: • Normal movement • Safe • Looks for norms as a comparison
Discussion: Tying in well with their well-developed task concept, patients on a level of Imitative Participation are able to evaluate their end product or performance in compliance with the norms set by themselves or society. Their product or performance is therefore of good quality and they are able to problem solve in order to improve the quality if required.
Participants' supporting quotations: • *"I think they will evaluate their product and be aware of its quality"* • *"They might look for norms to compare it to"* • *"They will try to problem solve to do it better"* • *"Product quality is good"*

4.9.4 Domain of relational contact with the body

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of their relational contact with the body?"

4.9.4.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with the body" domain for the level of Imitative Participation:

Theme 1: Acceptance of new body image, still working to recovery
Substantiating codes: • Realistic perception of the body • Aware of limitations and abilities • Able to compensate for limitations

Discussion:

The focus group participants concluded that patients on a level of Imitative Participation have accepted their new body image to the point of having a realistic perception of their abilities and limitations. They are able to work around these limitations by effectively adopting compensatory strategies. Despite this acceptance of their new body image, patients on this level are still motivated to improve their functioning, by attending therapy and continuing with the home exercise programmes that have been prescribed. They are motivated to improve their body functioning to the point of norm compliance.

Participants' supporting quotations:

- *"Acceptance of new body image"*
- *"…and work within their limitations"*
- *"I think they have a more realistic perception of their new body, although they still want their own body"*
- *"I think they are also the type of patients when they have a hemi arm, they want to improve it"*

Theme 2: Able to care for the hemiplegic side independently

Discussion:

When compared to the Passive Participation, patients on a level of Imitative Participation are also aware of the principles regarding the care for their hemiplegic side, although they are also able to implement these principles independently. Patients on this level can be seen correcting the position of their hemiplegic upper limb or performing stretches or proprioceptive inputs to their upper limb throughout the day without the need for reminding.

Participants' supporting quotations:

- *"I think they are aware of where it needs to be the entire time"*
- *"With someone to say, remember to do your home programme and then they can leave them"*
- *"These patients would probably take good care of the hemi arm if they didn't have good movement"*

4.9.5 Domain of relational contact with tools and materials

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of their relational contact with tools and materials?"

4.9.5.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with tools and materials" domain for the level of Imitative Participation:

Theme 1: Appropriate use of tools for their intended purpose (including assistive devices)

Substantiating codes:

- Able to use assistive devices
- Able to use novel tools with guidance initially

Discussion:

Patients on a level of Imitative Participation are able to use a variety of novel and basic tools and materials appropriately as indicated by the participants in the focus groups. They are able to name tools and describe their purpose. Norm compliance can be observed during tool handling. In terms of less familiar tools, they may require some initial guidance on their use (in the form of a person demonstrating or written instructions), after which they are able to continue independently.

Participants' supporting quotations:

- *"They do have appropriate use of tools and materials with improved quality"*
- *"Maybe for what it is intended only"*
- *"…we have been teaching him how to use a dressing stick and he has been using it for his pants but he can't work out that the same hook can be used to take his shoes off until it has been pointed out, he is then happy to carry on using it"*

Theme 2: Tools and materials used for their intended purpose

Substantiating codes:

- Little abstract thinking to change the purpose of tools to suit their needs

Discussion:

Patients on a level of Imitative Participation are unable to adapt tools and materials for their own needs due to poor abstract thinking and initiative. They therefore use tools for their intended purpose, without being able to think creatively in order to change the properties of tools as required.

Participants' supporting quotations:

- *"They might try something more abstract, but more with prompts or seeing someone else do it, therefore imitate"*
- *"…use a chopping board that has something you can stabilise it on, they will use it appropriately to compensate for that deficit"*

4.9.6 Domain of relational contact with the social world

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of their relational contact with the social world?"

4.9.6.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with the social world" domain for the level of Imitative Participation:

Theme 1: Norm compliant, aware of social cues. Able to handle a variety of situations

Substantiating codes:

- Able to imitate in unfamiliar situations
- Socially appropriate

Discussion:

Due to their ability to comply with the norms set by society, patients on a level of Imitative Participation are able to follow social cues. They act appropriately in a variety of situations, imitating the appropriate actions of others in unfamiliar situations in order to continue complying with the norms.

Participants' supporting quotations:

- *"They can be in unfamiliar situations and imitate"*
- *"Acts appropriately in all situations"*
- *"They are aware of social cues and quite compliant with the norms"*

Theme 2: Rely on others to initiate interaction
Substantiating codes: • Will interact with friends and family within a routine • Unable to sustain friendships independently • Involved in support groups
Discussion: As with the previous levels, the participants emphasised that patients on a level of Imitative Participation are still unable to initiate contact with others independently and therefore require some form of external intervention. Instead of the need for direct set-up and facilitation, patients on a level of Imitative Participation rather require a routine to follow in order to participate socially (e.g. a support group, church gathering). Patients on a level of Imitative Participation start to develop friendships with those around them, particularly others in a similar situation to them. Due to their continued egocentricity and inability to initiate interaction independently, these friendships tend to be relationships of convenience. These relationships only last as long as they are initiated by the other person.
Participants' supporting quotations: • *"They visit their family members, accompanied by a family member"* • *"So they tend to still rely on the other person"* • *"They start to develop little friendships with other patients that are similar to them"* • *"They aren't able to sustain their friendships"*

4.9.7 Domain of control of anxiety

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of their control of anxiety?"

4.9.7.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "control of anxiety" domain for the level of Imitative Participation:

Theme 1: Able to express, control and display a variety of emotions

Substantiating codes:

- Appropriate
- Compassion
- Able to apply coping mechanisms in familiar situations
- Can start emotional therapy

Discussion:

Participants agreed that patients on a level of Imitative Participation are able to express their emotions in a socially appropriate manner. They do not present with emotional lability as seen in Passive Participation and the lower levels, as they are able control their emotions such that it does not impair their functioning or result in non-compliance with the norm in familiar situations. They are able to express a variety of emotions, including more refined emotions such as compassion. On a level of Imitative Participation, patients can start to be included in psycho-social or emotional treatment and can be taught different coping mechanisms.

Participants' supporting quotations:

- *"There emotions aren't extreme"*
- *"There is a greater variety of emotions"*
- *"They can show things like compassion"*
- *"They have emotional control"*
- *"They will voice if they are anxious"*
- *"And you can teach them relaxation techniques"*

Theme 2: Anxious in unfamiliar situations

Substantiating codes:

- Unable to problem solve in unfamiliar situations
- Anxiety may impair function in an unfamiliar situation

Discussion:

Despite having control over their emotions, participants indicated that patients on a level of Imitative Participation become anxious in unfamiliar situations. Without someone to imitate and as a result of their decreased initiative, this anxiety may impair their functioning. They are unable to problem solve in these unfamiliar situations which could contribute to their increased levels of anxiety.

Participants' supporting quotations:

- *"In an unfamiliar situation, I don't think they would know how to make a plan and get quite anxious"*
- *"High in unfamiliar situations"*
- *"…as soon as there is an unknown thing out of your control, where there is a novel situation, or a crisis, then the control of anxiety is poor"*

4.9.8 Domain of ability to show initiative and make an effort

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of their ability to show initiative and make an effort?"

4.9.8.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "ability to show initiative and make an effort" domain for the level of Imitative Participation:

Theme 1: Able to initiate and put maximum effort into meaningful tasks

Substantiating codes:

- No extra effort is given (just meets the norm)
- Effort is sustained until task completion
- Follows a home exercise programme independently as part of a routine

Discussion:

Information gathered from the focus groups indicated that patients on a level of Imitative Participation are able to initiate familiar, meaningful tasks independently. For these patients to be able to initiate such tasks, a routine should be in place. They will then be able to continue independently. Maximum effort is also observed in such tasks, leading to successful task completion. Patients on a level of Imitative Participation are able to independently follow a home programme prescribed to them, without constant reminding to complete it. Despite the initiative and maximum effort seen on this level, these patients are unable to give extra effort while participating in tasks – they will meet the norm, no more and no less.

Participants' supporting quotations:

- *"I think at this level you are finding a lot more initiative in your home environment, taking control of tasks in your home environment that either you used to do or being able to do that without having to be reminded"*
- *"They will put a lot of effort into something that is meaningful and interesting to them"*
- *"What they need to get done they will do. They will not go above and beyond"*

Theme 2: Able to problem solve concrete problems. Unable to problem solve in unknown situations

Discussion:

Participants indicated that patients on a level of Imitative Participation are able to solve concrete problems faced during activity participation. These problems include how to fix a label to ensure that it is straight etc. These concrete problems are solved by referring back to norms and guidelines known to the patient. Abstract problems cause anxiety for a patient on a level of Imitative Participation and they do not possess the skills to solve these independently.

Participants' supporting quotations:

- *"…there is more problem solving around variables of a concrete problem"*
- *"Problem solves, takes initiative"*

4.9.9 Performance area of personal management

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of personal management?"

4.9.9.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "personal management" performance area for the level of Imitative Participation:

Theme 1: Independent

Substantiating codes:

- Showing personal style

Discussion:

Patients on a level of Imitative Participation are independent in all self-care tasks according to the information gathered in the focus groups. Their participation in such tasks is better within a routine. They are able to show personal preference and style in their choices and comply with the personal management norms set by society. They are intrinsically motivated to participate in personal management tasks in order to comply with norms and be accepted.

Participants' supporting quotations:

- *"They comply to the norms of personal management"*
- *"I think again they won't question the why, in terms of health management for example. They will have the script and they won't question why."*
- *"Independent"*
- *"Aware of their appearance"*
- *"Personal style and idiosyncrasy"*

Theme 2: Starting with IADL's

Substantiating codes:

- Within a routine
- Cleaning, cooking, washing dishes

Discussion:

On the level of Imitative Participation, patients are able to start performing domestic activities such as cooking, cleaning and washing the dishes. Again, these tasks are better performed within an established routine. These patients will perform tasks according to the norms, but are unable to exceed these norms.

Participants' supporting quotations:

- *"Domestic chores are also okay – they are cleaning, cooking, washing dishes"*
- *"They would have difficulties with budgeting"*

4.9.10 Performance area of social ability

Question asked:

"Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of social ability?"

4.9.10.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "social ability" performance area for the level of Imitative Participation:

Theme 1: Reciprocal
Substantiating codes: • Shows interest in others • Able to interact with familiar and unfamiliar people • Active participants in the community
Discussion: Despite their continued egocentric ways, participants indicated that patients on a level of Imitative Participation are able to show an interest in others. They can reciprocate interaction in a social setting where the interaction is predominantly led by the other person. On this level, patients are able to interact appropriately with familiar and unfamiliar people.
Participants' supporting quotations: • *"I do see them making the effort to initiate that to and from relationship"* • *"I think they do still have their friends"* • *"Their abilities have definitely improved because they now have reciprocal behaviour"*
Theme 2: Want to interact
Substantiating codes: • They want to be part of a community • Others must initiate the interaction or include it in a routine
Discussion: Participants indicated that patients on a level of Imitative Participation display intent to interact with others. Once discharged home, they express desires to be part of their community again, although they are unable to initiate interaction with their community. These patients are able to reintegrate into their communities with the initial facilitation of this reintegration done by someone else. After this initial facilitation, patients on a level of Imitative Participation are able to continue going to events such as support groups or church without facilitation if this forms part of their routine.

Participants' supporting quotations:

- *"And in a family, if they go shopping and things like that, they can say hello"*
- *"They can have those very basic conversations"*
- *"They want to be around other people"*
- *"…active social ability, maybe an active participant in the community – going back to church"*

4.9.11 Performance area of work ability

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of work ability?"

4.9.11.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "work ability" performance area for the level of Imitative Participation:

Theme 1: Open labour market

Substantiating codes:

- Reasonable accommodations
- Work dependent
- Predictable
- They are able to meet the job requirements, no extra effort
- Few social demands
- Able to study – short courses

Discussion:

As mentioned previously, the participants indicated that patients on a level of Imitative Participation present with total task concept. For this reason, they are able to participate appropriately in work-related activities. They are able to work within the open labour market, in an appropriate position (dependent on their physical abilities). The work environment needs to be predictable to avoid unfamiliar situations which could result in increased levels of anxiety. An element of repetition and structure is required; however patients on this level do not require constant supervision. Patients on the level of Imitative Participation are able to meet their job requirements, but are unable to exceed what is expected of them in an attempt to better their position in the work place.

Patients on a level of Imitative Participation are able to study or further their education in a structured and predictable academic setting, where they are required to follow the norms (with no expectation to exceed the norms). The type of course or content of their studies would be basic such as learning computer skills, rather than studying for an extended period of time.

Participants' supporting quotations:

- *"I think this is where we are looking at leaving, heading out of the sheltered, heading out into our open labour market with reasonable accommodations"*
- *"It is work dependent"*
- *"Low level open labour market"*
- *"I think to work independently, it would have to be repetitive work"*
- *"They will cope with adaptations to work"*
- *"It is often like a low wage, unskilled, open labour market, repetitive, structured environment"*
- *"Not with too many social demands"*
- *"…structured, predictable environment"*
- *"They can't go above and beyond"*
- *"They can learn a skill and be integrated into the work space"*
- *"I think they can study"*

4.9.12 Performance area of constructive use of free time

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Imitative Participation would present like in terms of constructive use of free time?"

4.9.12.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "constructive use of free time" performance area for the level of Imitative Participation:

Theme 1: Will participate in meaningful tasks
Substantiating codes: • Independent within a routine • Return to previous leisure tasks (dependent on their physical abilities) • Not competitive
Discussion: The participants of the focus groups concluded that on a level of Imitative Participation, patients will participate in tasks that are meaningful to them. As mentioned throughout, they do not require constant facilitation and guidance in order to participate, however participation is better within a routine that has been established by someone else. These patients are not competitive and therefore participation in sport is generally for fun or for their own benefit rather than for competition.
Participants' supporting quotations: • *"It needs to be structured for them otherwise they will do what everyone else is doing"* • *"A family member would be like, you used to go to bible study"* • *"Often will go back to what they know"* • *"…matching suitability and meaningfulness"* • *"They probably are not going to be competitive but they will participate"*

4.9.13 Discussion on the level of Imitative Participation

The participants of all four focus groups were in agreement with the domain descriptors for the level of Imitative Participation and literature was used to substantiate the data received to ensure that it is in line with the VdTMoCA and recovery following an ABI.

The data obtained from the focus group participants for the level of Imitative Participation is substantiated by the Rancho Los Amigos Scale,[55] the Glasgow Coma Scale,[56] Maslow's Hierarchy of Needs,[57] information provided by du Toit[8] in a number of papers that she presented on the VdTMoCA and information by de Witt.[53]

Following on from the discussion in the section on Passive Participation, the next levels according to the Rancho Los Amigos Scale are, Level 8: "Purposeful and Appropriate - Stand by assistance" and Level 9: "Purposeful and appropriate – Stand by assistance on request".[78] According to the data obtained from the focus group participants, these levels of the Rancho Los Amigos Scale correlate well with the level of Imitative participation in a patient following an ABI.

According to the Rancho Los Amigos scale, Level 8: "Purposeful and Appropriate – Stand by assistance", is characterised by the following[78]:

- Consistent orientation to place, person and time
- Completion of familiar tasks independently
- Improved recall of recent and remote information
- Initiation of familiar tasks within a routine
- Independent task participation
- Awareness of limitations, the patient requires minimal assistance to take corrective action
- Appropriate and wide range of emotional responses
- Compliance with the norms set by society
- Aware of others in a social situation

According to the Rancho Los Amigos scale, Level 9: “Purposeful and Appropriate – Stand by assistance on request”, is characterised by the following[78]:

- The ability to shift between tasks
- Initiation of familiar personal, household, work and leisure tasks independently
- Initiation of unfamiliar, non-routine personal, household, work and leisure tasks when requested to do so
- Increased insight into limitations and able to take appropriate corrective action with stand by assistance
- The ability to think about the consequences of their decisions with assistance
- Acknowledgement of others’ needs and feelings with stand-by assistance

Level 8 and 9 of the Rancho Los Amigos Scale correlate well with the data produced by the participants in this study for the level of Imitative Participation. Patients on a level of Imitative Participation present for the first time with intrinsic motivation to participate in tasks. As seen in the data obtained in the focus groups, as well as in levels 8 and 9 of the Rancho Los Amigos Scale, these patients present with full task concept, which allows them to complete tasks independently. Despite this, patients on this level continue to have poor initiation of tasks outside of an established routine. Unlike the previous levels though, patients on level 8 and 9 and Imitative Participation are able to produce a product of good quality and problem solve concrete problems to improve the quality. They are aware and compliant with the norms set by society.[78]

According to the Glasgow Coma Scale,[56] patients on a level of Imitative Participation present with a score of 15 out of 15, labelling the injury as “mild”. Patients on this level of GCS generally present with noticeable neurological impairments that may or may not be permanent. They are fully conscious and able to perform motor responses consistently on command (with the unaffected side). They are fully orientated to person, place, time and date and can actively participate in tasks. The GCS does not take into account any higher cognitive or social functions and therefore aspects such as initiative and relational contact with the social world are not

considered on this scale.[56] Patients on a level of Imitative Participation therefore function on the highest level in terms of the Glasgow Coma Scale.[56]

Maslow's Hierarchy of Needs,[57] Stage 4: "Esteem needs", is divided into two categories: esteem for oneself (independence, dignity) and the desire for respect from others or reputation (status). According to the data collected and analysed in this study, patients on a level of Imitative Participation are motivated to achieve something – money, status, normal function etc. They are therefore driven to independence and status, albeit still egocentric. They do not possess the internal drive to improve themselves or go above and beyond what is required of them, but they are motivated to meet the norms that are set by society.[57] On the level of Imitative Participation, patients tend to imitate those around them in order to fit into a group and gain acceptance, for example dressing to suit the fashion rather than practicality.

In order to further substantiate the data obtained during the focus groups, information provided by du Toit[8] and de Witt,[53] on mental health care users and their presentation according to the VdTMoCA, is discussed below.

According to du Toit,[8] the mental health care user on this level of Creative Ability presents with motivation that is predominantly directed towards complying with the norms that are set by society. The progression through the levels can be noted here, where patients on a level of Passive Participation's motivation is directed at establishing or realising these norms, but being unable to comply with them. Despite their consolidated task concept, patients on a level of Imitative Participation continue to become anxious in unfamiliar situations or in situations where the norm in unclear. The imitative action that predominates on this level results in a lack of initiative in tasks, hence the need for a routine. They are therefore able to do what is required of them – no more and no less. Due to their focus on complying with the norms, du Toit[8] states that these patients are able to evaluate their end products and problem solve to improve the final quality. They are also able to sustain their effort for task completion.[8]

De Witt[53] defines the presentation of mental health care users on the level of Imitative Participation in the four performance areas. In terms of personal

management, behaviour concerning self-care and domestic tasks is consistent and efficient. On this level, patients start to develop their own sense of style and an awareness of fashion. They may however still present with some inappropriateness in this regard, as they may dress in order to fit in with society, rather than to what suits their bodies. Patients on this level develop a sense for their financial management, although they are unable to control these independently.[53]

In terms of their social ability, de Witt[53] states that mental health care users on a level of Imitative Participation direct their social participation at belonging and respect. They are able to form mature and intimate relationships, albeit for egocentric reasons.[53] They are generally able to communicate efficiently and are aware of social cues. These patients are able to function well in familiar situations, but tend to present with heightened levels of anxiety in unfamiliar situations where the norm is unclear.[53]

According to de Witt[53] and du Toit,[8] mental health care users on a level of Imitative Participation are able to work within the open labour market. Their performance within the work place is goal-directed and norm compliant. Patients on this level are able to meet the standards expected of them at work, provided that the work is predictable, not demanding initiative or abstract problem solving.[8,53]

Mental health care users on a level of Imitative Participation tend to use their free time productively, provided these tasks are established into their routine. They start to develop an interest in different leisure time tasks, although these interests are often directed by what society dictates to be “fashionable” at the time. They are unable to independently initiate leisure tasks.[8,53]

As can be seen by the above information provided by du Toit[8] and de Witt[53] on the level of Imitative Participation in mental health care users, the data provided by the participants of this study on the presentation of patients following an ABI, is in line with the VdTMoCA, with no information contradicting the information initially laid out for the level by du Toit.[8,53]

4.9.14 Conclusion on the level of Imitative Participation

A patient following an ABI on a level of Imitative Participation focuses on complying with the norms set by society. Imitative participation is the first level where the patient presents with intrinsic motivation. In terms of patients following an ABI, this intrinsic motivation is directed towards attaining something, be it finances, acceptance or their previous level of functioning. They present with full task concept and are able to independently perform self-care as well as more advanced tasks, provided these tasks form part of their established routine, or are initially demonstrated by others. Patients on this level are able to comply with the norms set by society, which results in good quality products or performance and the ability to problem solve on a concrete level in order to improve this product. In a social setting, patients on a level of Imitative Participation are able to develop mature relationships, based on an egocentric need for acceptance. They are unable to handle unfamiliar situations independently and as a result, experience high levels of anxiety in such situations. In terms of the relation to their body, patients on a level of Imitative Participation are aware of the principles of caring for their new bodies and also able to implement these principles in their daily lives.

Due to their norm compliance and following of routines, these patients can follow a home exercise programme independently. They are however unable to go above the norms and therefore do no more and no less than is expected of them. In terms of work, patients on a level of Imitative Participation are able to work within the open labour market, in a predictable work environment. The data provided by the participants of this study is substantiated by level 8 and 9 of the Rancho Los Amigos Scale,[78] the Glasgow Coma Scale,[56] Maslow's Hierarchy of Needs[57] and by information provided by du Toit[8] and de Witt[53] on the VdTMoCA in psychiatry.

4.10 Creative Ability level of Active Participation

The sixth and last level of Creative Ability discussed in this study, is "Active Participation".[8] Patients on a level of Creative Ability higher than Active Participation generally do not require therapy anymore and are therefore not discussed in terms of patient assessment and treatment.[9]

Patients on a level of Active Participation are motivated to improve or change aspects of activity or behaviour that they have noticed to be a problem.[8] This improvement is however still based on their personal egocentric needs. They are now able to show initiative, original thought and are starting to develop an ability to think broadly.[8]

Table 4.9 below provides a summary of the themes and substantiating codes derived from the focus group data for the level of Active Participation.

The level of Active Participation is divided into the domains and performance areas described in Section 4.3. The participants were asked to discuss each domain and performance area according to each level of Creative Ability. The results obtained from the focus groups for these domains and performance areas for the level of Active Participation are presented as follows:

1. Question asked/prompt
2. Themes and codes identified
3. Discussion of the participants' responses regarding the specific domain
4. Supporting quotations provided by the participants

Finally, the level of Active Participation is concluded with a discussion of the focus group findings related to literature available on the VdTMoCA and ABI's.

Table 4.9: Themes and substantiating codes for Active Participation

ACTIVE PARTICIPATION		
Domains	**Themes**	**Substantiating codes**
Motivation	1. Directed to the improvement of self	• Physical, vocational, cognitive, social
Action	1. With originality, transcends the norms	• Action – aimed at meeting and exceeding the norms • Action – to improve own skills
Quality of product and task concept	1. Full task concept	• Abstract reasoning • Can adapt, modify, exceed, evaluate and upgrade
	2. Product or performance of good quality. Able to evaluate end product	• Meets and exceeds the norms
Relational contact with the body	1. Acceptance of new body image, still working for recovery	• Takes initiative for own recovery
	2. Too motivated or pre-occupied with improving	
Relational contact with tools and materials	1. Able to use familiar and novel tools appropriately	• With initiative
	2. Able to adapt equipment according to their needs	
Relational contact with the social world	1. Can interact appropriately with familiar and unfamiliar people	• Able to initiate and sustain contact • Can assist others • Have close interpersonal relationships
	2. Able to handle unpredictable situations independently	
	3. Involved in support groups	
Control of anxiety	1. Normal range of emotions	
	2. Able to control emotions independently	• Anxiety does not overwhelm function • Able to apply coping mechanisms
Ability to show initiative and make an effort	1. Able to show initiative in all situations	• Self-driven • Can identify and solve problems • Able to follow and improve on home exercise programme
	2. Able to sustain maximum effort for long term goals	• Persistent • Puts effort into others

4.10.1 Domain of motivation

Question asked:
"Let's talk about the last level of the outcome measure – Active Participation. Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of their motivation?"

4.10.1.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "motivation" domain for the level of Active Participation:

Theme 1: Directed to the improvement of self

Substantiating codes:

- Physical, vocational, cognitive and social

Discussion:

Participants indicated that patients functioning on a level of Active Participation are motivated to improve their own performance physically, socially, within task participation and in the work environment. They display an intrinsic motivation directed towards the betterment of the self. This motivation continues to remain egocentric, as they are motivated solely towards the improvement of their own situation. Despite this egocentricity, they can be seen doing things for the betterment of society, if the need to initiate such a task was found within themselves (i.e. starting a support group for stroke survivors could be seen as a selfless act, however the need arose from an egocentric personal need for the support group).

Participants' supporting quotations:

- *"They are motivated by something particular that they want to go back to"*
- *"They are more intrinsically motivated here"*
- *"Improvement of own skills"*
- *"They are often the people that see a stroke as a clean slate and second chance at life"*
- *"They will internalise what has happened to them so they can prevent another stroke"*

4.10.2 Domain of action

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of their action?"

4.10.2.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "action" domain for the level of Active Participation:

Theme 1: With originality, transcends the norms
Substantiating codes: • Action is aimed at improving their own skills • Action is aimed at meeting and exceeding the norms
Discussion: The participants of the focus groups concluded that the action of a patient on the level of Active Participation is original. They no longer require someone else to imitate or passively follow as they display the internal drive and initiative to participate. Not only are these patients norm compliant but they are also able to transcend (exceed) the norm in many spheres of their life. They are able to problem solve in order to better their performance or product. Their action can be seen as directed towards the improvement of their own skills and functioning.
Participants' supporting quotations: • *"Action is self-directed, self-fulfilled"* • *"Their action is towards improving own skills"* • *"These are the ones that take responsibility for their own exercise programme and their own health"*

4.10.3 Domain of quality of product or performance and task concept

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of their quality of product or performance and task concept?"

4.10.3.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "quality of product or performance and task concept" domain for the level of Active Participation:

Theme 1: Full task concept

Substantiating codes:

- Abstract reasoning
- Able to adapt, modify, exceed, evaluate and upgrade

Discussion:

Patients on a level of Active Participation have a full task concept according to the participants of the focus groups. They possess the skills required for abstract reasoning and are therefore able to adapt, modify, exceed, evaluate and upgrade tasks as required. They present with flexibility within a variety of familiar and unfamiliar tasks. Patients on this level understand the full concept of tasks and are able to employ reasoning skills when the concept is not so clear.

Participants' supporting quotations:

- *"Full task concept with flexibility within the task concept"*
- *"They can adapt, with variety"*
- *"They would be able to adapt, modify, exceed and evaluate to make it safer and to still have a good quality product"*

Theme 2: Product or performance of good quality

Substantiating codes:

- Able to evaluate the end product
- Meets and exceeds the norms

Discussion:

Patients on a level of Active Participation are able to meet and even exceed the norms when it comes to the quality of their end products or performance. They are able to find norms with which to compare their performance and realistically evaluate and problem solve in order to improve.

Participants' supporting quotations:

- *"They might be able to evaluate and determine how to make it better next time"*
- *"…to look good and still have a good norm compliance"*

4.10.4 Domain of relational contact with the body

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of their relational contact with the body?"

4.10.4.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with the body" domain for the level of Active Participation:

Theme 1: Acceptance of new body image, still working for recovery

Substantiating codes:

- Takes initiative for own recovery – will research new techniques
- Working to full recovery of function

Discussion:

Participants concluded that as with Imitative Participation, these patients have accepted their new bodies. They are realistic regarding their limitations and have already employed effective compensatory techniques in order to overcome these limitations. Despite this acceptance, patients on a level of Active Participation are not completely happy about their improvement (if they still have a weaker hemiplegic side) and are therefore constantly searching for ways in which to improve their function. These patients research new treatment techniques, attempt them at home and present them to their therapist during their treatment sessions.

Participants' supporting quotations:

- *"I don't think they are necessarily happy with their functioning but they have accepted it and I think they are always looking for new and improved treatment and techniques"*
- *"Often realistic about what their limitations are and how they can work around it"*
- *"Starting to do research regarding adaptations, modifications, new ways and compensatory techniques"*

Theme 2: Too motivated or pre-occupied with improving
Discussion: As can be seen in theme one above, a patient on a level of Active Participation is involved in their treatment process. They are constantly researching new treatment techniques and are generally motivated to participate in therapy sessions. This can go further than normal motivation, leading to the patients becoming pre-occupied with finding new techniques and exercises. At this level, therapists often have to ensure that the patient is able to maintain a healthy balance between working towards improving their function and the rest of their life.
Participants' supporting quotations: • *"Maybe too aware of what doesn't work so well"* • *"They do too many auto-assisted exercises because they want to improve"* • *"…sometimes on this level they are too motivated and they push themselves more than they should. You sort of have to put a bit of a pause on it and help them monitor because they still don't have realistic insight and understanding of what is going on."*

4.10.5 Domain of relational contact with tools and materials

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of their relational contact with tools and materials?"

4.10.5.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with tools and materials" domain for the level of Active Participation:

Theme 1: Able to use familiar tools and assistive devices appropriately
Substantiating codes: • Appropriate • With initiative

Discussion:

Participants emphasised that on a level of Active Participation, patients understand the purpose and function of tools and materials. They are therefore not only able to use familiar tools in an appropriate manner, but independently determine the purpose of novel tools and materials. They display initiative with tool and material handling and are able to appropriately identify their own assistive devices without assistance.

Participants' supporting quotations:

- *"They are able to work with most thing"*
- *"Maybe they would find assistive devices that we didn't even recommend to them in the shop and they will tell us about it"*
- *"They are the ones that will come back for splints"*

Theme 2: Able to adapt equipment according to their needs

Discussion:

Due to their understanding of the purpose of tools and materials and their initiative, patients on a level of Active Participation are able to adapt equipment according to their needs. This can be seen when patients make use of ordinary household equipment to assist with their daily functioning (i.e. independently change the function of a broom into a long handled sponge).

Participants' supporting quotations:

- *"…and adapt their behaviour"*
- *"They will make an interesting, like a water bottle to feed their plants because they can't do it on their own"*
- *"Can use a tools appropriately, even though it not necessarily what is was made to be used for"*
- *"They understand what materials are and can transcend above what they should be doing"*

4.10.6 Domain of relational contact with the social world

Question asked:

"Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of their relational contact with the social world?"

4.10.6.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "relational contact with the social world" domain for the level of Active Participation:

Theme 1: Interacts appropriately with familiar and unfamiliar people
Substantiating codes: • Able to initiate and sustain contact • Can assist others • Have close interpersonal relationships • Involved in support groups – may initiate or lead the group
Discussion: Participants concluded that patients on a level of Active Participation are aware and compliant with the norms of social interaction. They are therefore able to interact appropriately with familiar and unfamiliar people without cueing from others. They are aware of social cues and do not require facilitation in order to initiate interaction. On this level, patients are able to assist others and can often be seen giving other patients advice at therapy sessions and in support groups. They are able to initiate and sustain close interpersonal relationships.
Participants' supporting quotations: • *"They are often well connected in the community"* • *"They can maintain relationships"* • *"You can have a professional conversation with them"* • *"They are that patient, that if you are seeing a whole lot of different strokes and head injuries in the gym, they are the ones that will talk to other patients and families"*
Theme 2: Handles unpredictable situations independently
Discussion: Participants indicated that as a result of patients on a level of Active Participation's appropriate problem solving skills and initiative, they are able to handle unpredictable situations independently. They do not allow anxiety to impair their functioning, but rather assess the situation and problem solve accordingly.

Participants' supporting quotations:

- *"You can put them in more unpredictable situations"*
- *"They can deal with change and variety"*

4.10.7 Domain of control of anxiety

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of their control of anxiety?"

4.10.7.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe "control of anxiety" domain for the level of Active Participation:

Theme 1: Normal range of emotions

Discussion:

Patients on a level of Active Participation are able to display appropriate emotions in a variety of situations according to the information gathered in the focus groups. They have an extensive range of emotions, with refined emotions such as compassion and irritation.

Participants' supporting quotations:

- *"I think normal emotional response, normal range"*
- *"Normal"*

Theme 2: Controls emotions independently in all situations

Substantiating codes:

- Anxiety does not overwhelm function
- Able to apply coping mechanisms

Discussion:

Anxiety does not overwhelm the functioning of patients on a level of Active Participation. They are able to control their emotions in order to comply with the norms set by society. These patients are also able to learn and independently apply the appropriate coping mechanisms in a variety of situations. Despite anxiety being present in novel situations, patients on this level are able to control these emotions to the point of being able to continue functioning according to the norm.

Participants' supporting quotations:

- *"They may be able to apply skills on a day to day basis without someone having to help"*
- *"They are anxious in new situations but they can control and implement strategies to have an appropriate response"*
- *"It doesn't overwhelm their function"*

4.10.8 Domain of ability to show initiative and make an effort

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of their ability to show initiative and make an effort?"

4.10.8.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "ability to show initiative and make an effort" domain for the level of Active Participation:

Theme 1: Shows initiative in all situations

Substantiating codes:

- Self-driven
- Identifies and solves problems
- Follows and improves on home exercise programmes

Discussion:

According to the data obtained in the focus groups, patients on a level of Active Participation are able to show initiative in all situations. This can be seen in their ability to find successful, new solutions during activity participation. They do not require facilitation or guidance from others during participation in novel or familiar tasks. Patients on this level are also able to independently follow a home exercise programme, as well as improve on this programme by performing their own research as previously mentioned.

Participants' supporting quotations:

- *"They can take initiative, it is not necessarily guided by someone else or guidelines"*
- *"They can follow a home exercise programme"*
- *"They problem solve themselves"*
- *"They can find successful solutions, new or unique applications"*

Theme 2: Sustains maximum effort to reach long term goals

Substantiating codes:

- Persistent
- Puts effort into others

Discussion:

Patients on a level of Active Participation are not only able to sustain their effort until task completion, but also able to have long term goals to work towards. Their effort is sustained in tasks that are interesting to them as well as tasks which need to be done for the sake of being completed. These patients can be seen starting support groups or initiating projects within the ABI community.

Participants' supporting quotations:

- *"…put effort into others"*
- *"…they will want to start stroke support groups"*
- *"They will put effort into all tasks, even ones that aren't necessarily within their interest"*
- *"Not just sustaining until the end of the task. They can actually sustain a drive to achieve a long term goal."*

4.10.9 Performance area of personal management

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of personal management?"

4.10.9.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "personal management" performance area for the level of Active Participation:

Theme 1: Independent

Substantiating codes:

- Good quality
- Personal style evident

Discussion:

On a level of Active Participation, patients are able to perform personal management tasks independently and with good quality according to the participants. They do not require a routine. They display personal style appropriately with no guidance.

Participants' supporting quotations:

- *"Independent"*
- *"Good quality"*
- *"I think it is independent, above the norm. Personal style included."*

Theme 2: Independent in IADL's

Substantiating codes:

- Personal affairs

Discussion:

Patients on a level of Active Participation are now able to perform domestic as well as more complicated instrumental activity of daily living tasks such as budgeting and managing their personal affairs. They may require assistance for this, from educated individuals (such as financial advisors etc.), although this assistance will be no different to anyone requiring assistance from professionals.

Participants' supporting quotations:

- *"They are probably at a level that they would have insight into their personal affairs"*
- *"They also may be able to take on a role as a carer"*
- *"Higher IADL's"*

4.10.10 Performance area of social ability

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of social ability?"

4.10.10.1 Themes and codes identified

The following two themes and substantiating codes were identified to describe the "social ability" performance area for the level of Active Participation:

Theme 1: Appropriate with familiar and unfamiliar people
Substantiating codes: • Able to differentiate between the social norms with familiar and unfamiliar people
Discussion: As mentioned previously, patients on a level of Active Participation are able to appropriately communicate with familiar and unfamiliar people. They are able to hold professional conversations, as well as communicate via email or over the telephone. These patients no longer require face to face interaction in order to infer the social cues from the other person.
Participants' supporting quotations: • *"I think both familiar and unfamiliar, you would know how to speak to the cashier in the shop"* • *"By active, you can start having no face to face relationships"*
Theme 2: Forms relationships independently
Discussion: On a level of Active Participation, patients are able to form relationships independently as they have the initiative and drive required for such interaction. They do not need someone to demonstrate or initiate interaction on their behalf and are seen having relationships that are stable, mature and intimate. The content of conversation with these patients is no longer egocentric.
Participants' supporting quotations: • *"Able to form relationships independently"* • *"I think you are now at a point where your relationships are more stable, they are mature and they are intimate"*

4.10.11 Performance area of work ability

Question asked: "Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of work ability?"

4.10.11.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the “work ability” performance area for the level of Active Participation:

Theme 1: Open labour market
Substantiating codes: • Supervisory or managerial positions • Suggests own reasonable accommodations • Occupation dependent • Works towards a promotion/improving self • Able to study – long term (degrees, diplomas)
Discussion: Participants emphasised that patients on a level of Active Participation are able to work within the open labour market. These patients can work in supervisory and managerial positions, where they are required to take responsibility for themselves, their workload and others within the work place. They are able to suggest their own reasonable accommodations in order to improve their performance and productivity and are then able to make use of these adaptations with no difficulty. Again, this employment would be occupation dependent, especially in the case where a patient continues to present with a hemiplegic upper or lower limb on the level of Active Participation. On this level, patients are able to study in order to further their knowledge and advance their careers. Longer term studying could be done (i.e. university degrees).

Participants' supporting quotations:

- *"Productive, they work more efficiently, they see how can they improve their productivity or develop systems to improve"*
- *"They are able to problem solve better and deal with challenges"*
- *"They do more than their job descriptions"*
- *"They can assume responsibility within the work force"*
- *"With reasonable accommodations"*
- *"There is still a limitation in terms of which jobs are appropriate, but definitely open labour market, able to meet all job requirements of an appropriately selected job"*
- *"You would put these people in supervisor roles"*
- *"They will suggest their own adaptations in the work place"*

4.10.12 Performance area of constructive use of free time

Question asked:
"Is there anything that stands out for you in terms of what a neurological patient on a level of Active Participation would present like in terms of constructive use of free time?"

4.10.12.1 Themes and codes identified

The following theme and substantiating codes were identified to describe the "constructive use of free time" performance area for the level of Active Participation:

Theme 1: Constructive

Substantiating codes:

- Initiates projects
- Creative
- Able to explore new tasks
- Aware of the benefits of leisure participation
- Able to adapt tasks to suit physical abilities

Discussion:
A patient on the level of Active Participation is able to independently use their free time constructively according to the information gathered in the focus groups. They are able to explore new leisure tasks and adapt tasks as required according to their physical abilities. These patients are aware of the benefits of leisure participation and can independently initiate engagement with such tasks for their own benefit.
Participants' supporting quotations: • *"They will return to what they love"* • *"…at this point you are starting to explore with leisure participation"* • *"Using that initiative to adapt the task for yourself"* • *"Yes, problem solve throughout every aspect"* • *"They might have a greater awareness to incorporate these things as a stress release"*

4.10.13 Discussion on the level of Active Participation

The participants of all four focus groups were in agreement with the domain descriptors for the level of Active Participation. Literature was used to substantiate the data received to ensure that it is in line with the VdTMoCA and recovery following an ABI.

The data obtained from the focus group participants for the level of Active Participation is substantiated by the Rancho Los Amigos Scale,[78] the Glasgow Coma Scale,[56] Maslow's Hierarchy of Needs,[57] information provided by du Toit[8] in a number of papers that she presented on the VdTMoCA and information by de Witt[53] on the VdTMoCA.

Following on from the discussion in the section on Imitative Participation, the next level according to the Rancho Los Amigos Scale is; Level 10: "Purposeful and appropriate - Modified independence".[78] According to the data obtained from the focus group participants, this level of the Rancho Los Amigos Scale correlates well with the level of Active participation in a patient following an ABI.

According to the Rancho Los Amigos scale, Level 10: “Purposeful and appropriate – Modified independence” is characterised by the following[78]:

- The ability to handle a number of tasks simultaneously in a variety of environments
- Independent and appropriate identification or creation of assistive devices
- Independent initiation and completion of familiar and unfamiliar personal, household, work, community and leisure tasks (may require extra time or compensatory strategies in order to complete the task)
- Increased insight into impairments – able to independently problem solve to avoid issues during task participation
- The ability to recognise and act on the feelings and needs of others
- Consistent and appropriate social interaction

Level 10 of the Rancho Los Amigos Scale correlates well with the data produced by the participants in this study for the level of Active Participation. Patients on a level of Active Participation are able to function independently in their household, work and community environments. As seen by the data obtained in the focus groups, as well as in Level 10 of the Rancho Los Amigos Scale, patients on this level present with total task concept and initiative. This allows them to complete a variety of tasks independently, without the need for an established routine. Patients on this level are therefore able to adapt their behaviour, problem solve and adapt equipment according to their needs. Much like the previous level, patients on this level are able to produce a product of good quality, although they are now able to problem solve in familiar and unfamiliar situations. They are aware of the norms and even able to transcend these norms if required.[78]

According to the Glasgow Coma Scale,[56] patients on a level of Active Participation present with a score of 15 out of 15, labelling the injury as “mild”. Patients on this level of GCS generally present with noticeable neurological impairments that may or may not be permanent. They are fully conscious and able to perform motor responses consistently on command (with the unaffected side). They are fully orientated to person, place, time and date and can actively participate in tasks. The GCS does not take into account any higher cognitive or social functions and therefore aspects such as initiative and relational contact with the social world are not

considered on this scale. Patients on a level of Active Participation therefore function on the highest level in terms of the Glasgow Coma Scale.[56]

Maslow's Hierarchy of Needs,[57] Stage 5: "Self-Actualisation", is the highest level of needs described in the hierarchy. It involves the realisation of personal potential. Maslow[57] defines this stage as "to become everything one is capable of being". According to the data collected and analysed in this study, patients on a level of Active Participation are motivated to improve their own functioning (physically, cognitively, socially and vocationally). Just like is suggested on this stage of Maslow's Hierarchy of Needs, patients following an ABI on a level of Active Participation are motivated to improve their own skills in order to meet or exceed the norms set by society. They are able to go above and beyond what is expected of them in order to improve their functioning.[57]

In order to further substantiate the data obtained during the focus groups, information provided by du Toit[8] and de Witt,[53] on mental health care users and their presentation according to the VdTMoCA, is discussed below.

According to du Toit,[8] a mental health care user on this level presents with motivation that is directed towards changing or improving behaviour or aspects of an activity that they have identified as being problematic. The motives of patients on this level remain egocentric, although others may indirectly benefit from their actions. According to de Witt,[53] the main purpose of these patients' action is to save personal time, earn a promotion, earn money or gain attention from others. Patients on this level present with initiative and original thought. Patients on a level of Active Participation present with a wide array of emotional responses and they are able to control their emotions in a variety of situations. These patients are able to sustain effort for longer periods of times in order to achieve long term goals.[8]

De Witt[53] defines the presentation of mental health care users on the level of Active Participation in the four performance areas. In terms of personal management, patients on this level of Creative Ability are independent, with personal style evident. They are aware and compliant with the norms set by society. They are able to live independently, caring for themselves, their finances, their household and possibly others as well.[53]

In terms of their social ability, de Witt[53] states that mental health care users on a level of Active Participation are able to form mature, intimate and lasting friendships, despite these continuing to be for egocentric reasons. This egocentricity is not the same as previous levels, where the content of the conversation is egocentric, but rather the reason for developing the friendships is egocentric and centred around what they can get out of the relationship. They are actively involved in their communities and may even take responsibilities for projects within the community.[53]

According to de Witt[53] and du Toit,[8] mental health care users on a level of Active Participation are able to work within the open labour market. Their performance within the work place is goal-directed and norm compliant. Patients on this level are able to meet the standards expected of them at work and even exceed these in order to gain a promotion. Patients on a level of Active Participation are able to work in supervisory and managerial positions.[8,53]

Mental health care users on a level of Active Participation tend to use their free time constructively. They possess a wide range of interests and personal gratification and social acceptance remain important on this level. They are able to identify appropriate leisure tasks and independently initiate them.[8,53]

As can be seen by the above information provided by du Toit[8] and de Witt[53] on the level of Active Participation in mental health care users, the data provided by the participants of this study on the presentation of patients following an ABI, is in line with the VdTMoCA, with no information contradicting the information initially laid out for the level by du Toit.[8]

4.10.14 Conclusion on the level of Active Participation

A patient following an ABI on a level of Active Participation's focus is on improving their own functioning (socially, vocationally, physically or cognitively). Patients on a level of Active Participation present with intrinsic motivation. This is the first level where the patients display initiative in a variety of situations and are therefore able to problem solve, live independently and improve their functioning. They present with total task concept and are therefore able to independently perform self-care as well as more advanced tasks, without the need for an established routine. Patients on this

level are able to comply with and possibly even exceed the norms set by society, which results in good quality of product or performance. In a social setting, patients on a level of Active Participation are able to develop intimate, mature and lasting relationships independently. They are able to handle unfamiliar situations independently and therefore do not allow anxiety to impair their function. In terms of the relational contact with their body, patients on a level of Active Participation are aware of the principles of caring for their new bodies and also able to independently implement these principles in their daily lives. They are able to follow a home exercise programme independently, as well as improve on this programme through research of their own. In terms of work, patients on a level of Active Participation are able to work within the open labour market, in managerial or supervisory positions. The data provided by the participants of this study is substantiated by level 10 of the Rancho Los Amigos Scale,[55] the Glasgow Coma Scale[56] and Maslow's Hierarchy of Needs.[57] It is further substantiated by information provided by du Toit[8] and de Witt[53] on the VdTMoCA for mental health care users and children.

4.11 Progression of the domains and performance areas

As seen in the information above, the focus groups led to data rich in information regarding Creative Ability in the field of neurology. In order to conclude this section on objective one, Table 4.10 provides a visual representation of the themes for the domains and performance areas per level of Creative Ability. Table 4.10 allows us to see that the levels are consecutive, with logical progression and improvement through the different levels at a consistent rate.

The themes and substantiating codes derived from the focus group data were translated into domain descriptors by the researcher and can be found in Annexure H. This was done through the review of literature as seen in the discussions above, to ensure that all descriptors remained in line with the progression of patients' function following an ABI and in line with the VdTMoCA.

Table 4.10: Progression of the domains and performance areas for all 6 levels of Creative Ability

	Tone	Self-Differentiation	Self-Presentation	Passive Participation	Imitative Participation	Active Participation
Motivation	• Motivationally blank • Physiological maintenance	• Egocentric • To differentiate self	• To present self • Unsure, externally motivated	• Directed to the attainment of skills • Externally motivated	• Intrinsically motivated to achieve something	• Directed to the improvement of self
Action	• Predestructive • Reflexive, involuntary	• Destructive • Incidentally constructive • Emergence of participation	• Explorative, facilitated • 1-2 steps (global) • 3-4 (step by step)	• Skill/product centred, therapist directed, safe • 2-4 steps (global) • 5-7 (step by step)	• Imitative, norm directed • Imitate premorbid norms • 7-10 steps	• With originality, transcends norms
Quality of product and task concept	• None	• Emergence of participation in basic need tasks • Poor quality of product/performance	• Partial task concept • Poor quality of product/ erformance	• Consolidated task concept (basic tasks) • Aware of norms, concrete evaluation • Facilitation required	• Full task concept • Productor performance of good quality. Evaluates product	• Full task concept • Product or performance of good quality. Evaluate product
Relational contact with the body	• No body awareness • Neglect of affected • Reflexive	• Emerging body concept • Neglect of the affected side	• Increased awareness of abilities • Learned non-use of the affected side	• Aware of affected limb and theory regarding care • Purposeful, safe use of body (facilitated)	• Acceptance of new body image, working for recovery • Able to care for hemiplegic side	• Acceptance of new body image, working for recovery • Too motivated/pre-occupied to recover
Relational contact with tools and materials	• None	• Basic, familiar • Inappropriate use • Requires maximum facilitation	• Basic • Aware of norms, not compliant	• Aware of the purpose of tools • Able to use assistive devices with guidance	• Appropriate use of tools for their intended purpose • Able to use assistive devices	• Able to use familiar tools and assistive devices appropriately • Able to adapt equipment with help
Relational contact with the social world	• Reflexive • Fleeting awareness of familiar voices and faces	• Fleeting/brief contact with familiar people • Unaware of social norms	• Egocentric • Automatic speech • Emerging intent to interact	• Superificial, concrete, current • Interacts with facilitation • Aware of norms	• Norm compliant • Able to hand a variety of situations • Rely on others to initiate	• Interacts with familiar and unfamiliar • Handles unpredictable situations
Control of anxiety	• No anxiety	• Labile • Comfort and discomfort • Low frustration tolerance	• Labile, poor emotional control • Fearful, low self-esteem	• Names and recognises concrete emotions • Depression	• Expresses,controls variety of emotions • Anxious in unfamiliar situation	• Normal range of emotions • Controls emotions in all situations

	Tone	Self-Differentiation	Self-Presentation	Passive Participation	Imitative Participation	Active Participation
Ability to show initiative and make an effort	• None	• Unable to initiate • Effort in response to physiological need	• Poor initiative • Poor frustration tolerance, unable to sustain effort	• Able to initiate and put maximum effort into meaningful tasks • Unable to problemsolve	• Able to initiate and put maximum effort • Able to problem solve concrete problems	• Shows initiative in all situations • Sustains maximum effort to reach long term goals
Personal management	• Totally dependent	• Dependent • Able to participatie with maximum facilitation	• Dependent, aware of norms • Responds better to routine	• Participates independently in BADL's within routine • Starting simple IADL's	• Independent • Starting IADL's	• Independent • Independent in IADL's
Social ability	• None	• Egocentric • Able to recognise familiar people	• One on one • Dependent on others. Poor compliance	• Able to interact with set-up • Can be included in groups	• Reciprocal • Want to interact	• Appropriate with familiar and unfamiliar • Forms relationships independently
Work ability	• None	• None	• Sheltered employment	• Sheltered employment	• Open labour market	• Open labour market
Constructive use of free time	• None	• None	• Passive	• Passive	• Will participate in meaningful tasks	• Constructive

4.12 Objective 2 - Development and design of the outcome measure

Following the development of domain descriptors in Objective one, the outcome measure had to be developed. This was therefore the stage where the outcome measure needed to be labelled. As the VdTMoCA was central to the development of this outcome measure, with its key components being motivation and action,[8] the researcher felt it necessary to include these terms in the label. The final name of the outcome measure therefore became the Motivation and Action in Neurological Rehabilitation Outcome Measure, with the acronym MANROM.

Scale development of the MANROM was guided by the first six levels of Creative Ability, namely Tone, Self-Differentiation, Self-Presentation, Passive Participation, Imitative Participation and Active Participation.[8] Despite the VdTMoCA including a total of 9 levels, the higher levels are not included in the MANROM as people functioning on these levels are not generally seen for therapy, as they are competitive and contributing members of society and therefore do not require active rehabilitation.[29]

The review of literature as well as input from an expert in neurological occupational therapy, with a strong background in the VdTMoCA, was considered while deciding on the format for the MANROM. Review of the measures mentioned in Table 2.5, namely APOM,[29] CPA,[51] FLOM[75] and the OTCAP[8] provided valuable insight into the format required for the MANROM. An example of these measures and their formats can be found below in Figure 4.4,[29,50] Figure 4.5[29,50] and Figure 4.6.[29,50]

The format of the MANROM was specifically developed for use by occupational therapists working in neurology to determine the level of motivation and action of their patients, as well as to measure the outcomes of their intervention. The format had to be in line with their level of knowledge and applicable to their field of work (for quick and easy identification of the description that corresponds with the patient's presentation). It was important that the format be user-friendly and explanatory. The framework of the MANROM can be found in Annexure F. The finalised MANROM can be found in Annexure H.

MOTIVATION DESCRIBED IN LEVELS OF PARTICIPATION

Item	Tone 1 , 2, 3	Self differentiation 4, 5, 6	Self presentation 7, 8, 9,	Participation		
				Passive 10, 11, 12	Imitative 13, 14, 15	Active 16, 17, 18
Active involvement	Makes no effort to engage in activity.	Makes minimal effort, incidental response, shows enjoyment for brief moments.	Puts in effort, willing to try out and present self. Effort usually ends abruptly and before activity is completed.	Muster courage and able to maintain effort if no problems are encountered. Shows enjoyment during the task.	Sustains consistent effort for a task. Enjoyment motivates him to participate in more challenging tasks.	Sustains consistent effort and generates originality. Enjoyment leads to more creative participation in future situations.
Motives and drives	Basic drive to maintain the body in homeostasis, no signs of will to live, quality of life dependent on nursing care.	Willing to participate if basic drives needs are satisfied.	Egocentric motives, belonging and approval from selected persons drive the person to action.	Approval and belonging to a group drive the person to action.	Positive self-esteem drives the person to action	Striving for self actualization and values drive action.
Shows interest	Shows no need for stimulation or participation in activities.	Shows interest in activities that will satisfy basic and immediate needs.	Shows interest in stimulation and activities, interest not sustained.	Shows interest in variety of activities, sustains interest in preferred and known activities.	Able to show interest in preferred and non-preferred activities, willing to learn new skills.	Interested in preferred and non-preferred activities, execution with originality, adapts to make non-preferred activities more interesting.

Figure 4.4: Example of the format of the APOM

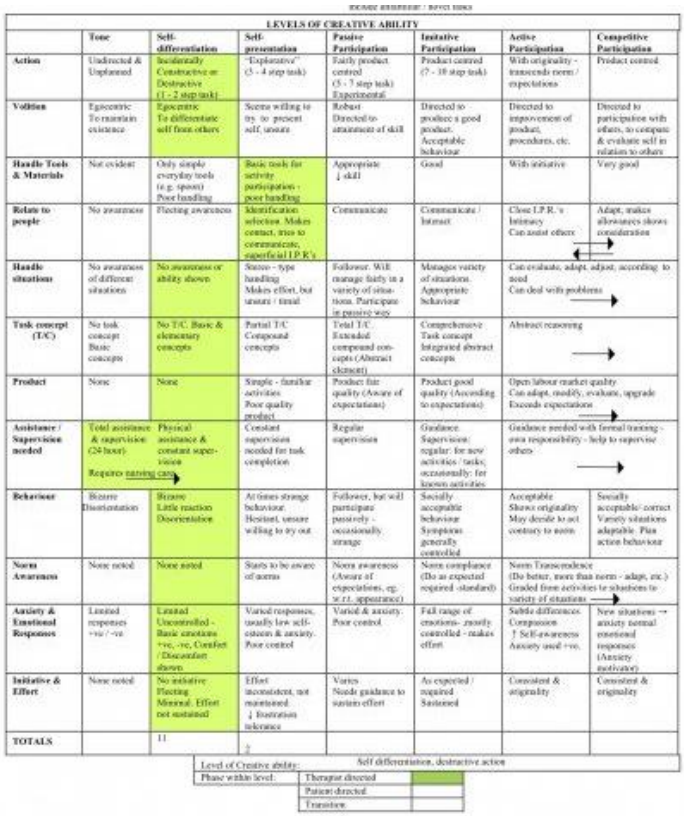

Figure 4.5: Example of the format of the CPA

Mental illness		Yes	No
Level 1-Tone	There is life and that is all i.e. defenseless, dependant, incapable		
Level 2 Self-differentiation	Obviously mentally ill/intellectualy impaired		
	Cannot give account of self/cannot explain own feelings & actions		
	Range of emotions is very limited (Needs to fulfill basic needs like hunger)		
	Behaviour is considerably influenced by delusions or hallucinations/intellectual impairment/mental illness		
Level 3-Intentional explorative action	Start to become aware of the mental illness		
	Gives poor self account (cannot explain own feelings and actions)		
	It is difficult to understand the difference between the real world and delusions and hallucinations		
	Full range of emotions evident		
	High level of anxiety present in unknown situations		
	Has low self esteem		
Level 4 Norm directed action	Disorder not always evident		
	Able to give self account		
	Some mild symptoms are visible eg. Some depressive mood		
	Emotional response is appropriate for the situation		
	Anxiety control is poor		
Level 5 - Norm compliance action	User seems normal, illness not evident		
	Compliant with medication		
	Gives good account of self		
	Has intellectual and emotional insight into mental illness		

Figure 4.6: Example of the format of the FLOM

4.13 Conclusion

This chapter began with a discussion of the demographic information of the participants of this study. The themes and substantiating codes, which emerged from the thematic analysis of the focus group data, were then discussed. Literature available on ABI's and the VdTMoCA was then used to substantiate and back-up the data produced, as well as to assist the researcher in converting the data from themes and codes into domain descriptors to be included in the MANROM.

Chapter 4 concluded with a discussion of the results of the second objective, which was an academic and theoretical process which entailed the designing and developing of the outcome measure – the MANROM.

In Chapter 5, the researcher concludes the findings of this study. This includes a reflection of the study as well as reporting on the limitations and strengths during the research process. The researcher provides advice on the use of the MANROM in practice as well as recommendations regarding future research in this field of study.

CHAPTER 5 :
CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1 Introduction

In Chapter 1, the researcher described the study's aims and objectives as follows:

The aim of the research was to determine the domain descriptors per level of Creative Ability according to each domain specified, for a VdTMoCA-based outcome measure for occupational therapists working in neurological rehabilitation to successfully assess a patient's motivation and action. To achieve this aim, the following objectives were developed:

- Objective 1: To develop domain descriptors for each domain for the first six levels of Creative Ability
- Objective 2: To design and develop a user-friendly outcome measure using the information gathered in the first objective

These objectives were achieved with the assistance of participants (neurological occupational therapists, practising as clinicians or in education) who participated in focus groups as described in the methodology of this study in Chapter 3. The themes and substantiating codes developed during these focus groups were converted into domain descriptors and discussed in relation to literature in Chapter 4.

Chapter 5 provides the final conclusion to this study, in which each objective is briefly discussed. Themes identified during the study will also be summarised. Furthermore, recommendations regarding the use of the outcome measure are then given, followed by recommendations regarding future research on this topic. The study is terminated with a final conclusion.

5.2 Conclusions

5.2.1 Conclusion: Objective one

As discussed above, the first objective was to develop domain descriptors for the first six levels of Creative Ability for neurological patients. Data was gathered during four focus groups with occupational therapists working in neurology. The focus groups were facilitated and transcribed verbatim by the researcher. Thematic analysis was

used to develop themes and substantiating codes that represent the data set. The first objective was met when the themes and codes were transcribed into domain descriptors with the use of literature.

A qualitative descriptive design was used. The method of data collection was through the use focus groups with occupational therapists working in neurology (in practice or education). This method of design and data collection was the preferred method to address a real, theory practice gap in the clinical field of neurological occupational therapy. The participatory nature of the focus groups allowed the researcher to gain valuable insights into therapists' views on the matter at hand as well as practical examples of the presentations of neurological patients on different levels of functioning. A number of the therapists indicated their enthusiasm towards the development of the outcome measure – indicating that there genuinely is a gap in the available outcome measures for occupational therapists working in neurology.

Focus groups are known to be an appropriate method used to explore the unknown during the first stages of the research process.[32] Focus groups were a useful method of data collection in this study as they provided the researcher with useful and relevant data. The group process within each focus group allowed therapists to enter into valuable discussions regarding certain subjects, which ultimately increased the value and depth of the data collected. The researcher ensured that the planning of the focus groups was done meticulously in order to eliminate three common mistakes when focus groups are used as scientific intervention. The three common mistakes include methodological, procedural and analytical mistakes.[80] Methodological mistakes were avoided by selecting applicable aims for the focus groups. The focus groups aimed to explore the therapists' knowledge regarding the levels of Creative Ability in neurology and therefore planning and organisation prior to the focus groups ensured that this aim was met. Procedural mistakes were prevented by ensuring that the questions and guidelines given to the participants were appropriate and that the participants were selected prudently. Lastly, analytical mistakes were avoided through the use of an independent coder to recode the transcriptions, as well as comment on the developed themes and substantiating codes.[80]

Thematic analysis proved to be an effective method of data analysis, as Braun and Clarke's[65] six step process guided the researcher in the analysis of the data while not biasing the researcher or skewing the data. It allowed the researcher to identify appropriate themes and substantiating codes that represent the data set as a whole. The use of an independent coder also proved effective. A discussion between the independent coder and the researcher was held after both parties finished analysing the data, to reach a consensus regarding the themes and substantiating codes. The fact that the independent coder was both an expert in the field of neurological occupational therapy as well as in the VdTMoCA ensured that the independent coder could provide valuable insights into the data. The finalised themes derived from this process can be found in Table 5.1.

Table 5.1: Summary of the themes derived from the focus groups

TONE
Motivation: Motivationally blank, physiological maintenance **Action:** Pre-destructive, reflexive, involuntary **Quality of product or performance and task concept:** None **Relational contact with the body:** No body awareness, neglect of affected, reflexive **Relational contact with tools and materials:** None **Relational contact with the social world:** Reflexive, fleeting awareness of familiar voices and faces **Control of anxiety:** No anxiety **Ability to show initiative and make an effort:** None **Personal management:** Totally dependent **Social ability:** None **Work ability:** None **Constructive use of free time:** None
SELF-DIFFERENTIATION
Motivation: Egocentric, to differentiate self **Action:** Destructive, incidentally constructive, emergence of participation **Quality of product or performance and task concept:** Emergence of participation in basic need tasks, poor quality of product or performance **Relational contact with the body:** Emerging body concept, neglect of the affected limb **Relational contact with tools and materials:** Basic, familiar, inappropriate use, requires maximum facilitation **Relational contact with the social world:** Fleeting or brief contact with familiar people, unaware of the social norms **Control of anxiety:** Labile, comfort and discomfort evident, low frustration tolerance **Ability to show initiative and make an effort:** Unable to initiate, effort is in response to physiological needs **Personal management:** Dependent, able to participate with maximum facilitation **Social ability:** Egocentric, able to recognise familiar people **Work ability:** None **Constructive use of free time:** None

SELF-PRESENTATION
Motivation: To present self, unsure, externally motivated **Action:** Explorative, facilitated, 1-2 steps (global), 3-4 steps (step by step) **Quality of product or performance and task concept:** Partial task concept, poor quality of product or performance **Relational contact with the body:** Increased awareness of abilities, learned non-use **Relational contact with tools and materials:** Basic, aware of norms, not compliant **Relational contact with the social world:** Egocentric, automatic speech, emerging intent to participate **Control of anxiety:** Labile, poor emotional control, fearful, low self-esteem **Ability to show initiative and make an effort:** Poor initiative, poor frustration tolerance, unable to sustain **Personal management:** Dependent, aware of norms, responds better to a routine **Social ability:** One on one, dependent on others, poor compliance **Work ability:** Sheltered **Constructive use of free time:** Passive
PASSIVE PARTICIPATION
Motivation: Directed to the attainment of skills, externally motivated **Action:** Skills or product centred, therapist directed, safe, 2-4 steps (global), 5-7 steps (step by step) **Quality of product or performance and task concept:** Consolidated task concept (basic tasks), aware of norms, concrete evaluation, facilitation required **Relational contact with the body:** Aware of the affected limb and theory regarding care, purposeful, safe use of the body (facilitated) **Relational contact with tools and materials:** Aware of the purpose of tools, able to use assistive devices with guidance **Relational contact with the social world:** Superficial, concrete, current, interacts with facilitation, aware of norms **Control of anxiety:** Names and recognises concrete emotions, depression **Ability to show initiative and make an effort:** Able to initiate and sustain maximum effort in meaningful tasks, unable to problem solve **Personal management:** Participates independently in BADL's within a routine, starting simple IADL's **Social ability:** Able to interact with set-up, can be included in groups **Work ability:** Sheltered **Constructive use of free time:** Passive
IMITATIVE PARTICIPATION
Motivation: Intrinsically motivated to achieve something **Action:** Imitative, norm directed, 7-10 steps **Quality of product or performance and task concept:** Full task concept, product or performance of good quality, evaluates product **Relational contact with the body:** Acceptance of new body image, working for recovery, able to care for hemiplegic side **Relational contact with tools and materials:** Appropriate use of tools for their intended purpose, able to use assistive devices **Relational contact with the social world:** Norm complaint, able to handle a variety of situations, rely on others to initiate **Control of anxiety:** Expresses, controls and displays a variety of emotions, anxious in unfamiliar situations **Ability to show initiative and make an effort:** Able to initiate and sustain maximum effort, able to problem solve concrete problems

Personal management: Independent, starting IADL's **Social ability:** Reciprocal, want to interact **Work ability:** Open labour market **Constructive use of free time:** Will participate in meaningful tasks
ACTIVE PARTICIPATION
Motivation: Directed to the improvement of self **Action:** With originality, transcend norms **Quality of product or performance and task concept:** Full task concept, product or performance of good quality, evaluates product **Relational contact with the body:** Acceptance of new body image, working for recovery, too motivated or pre-occupied **Relational contact with tools and materials:** Able to use familiar tools and assistive devices appropriately, able to adapt equipment **Relational contact with the social world:** Interacts with familiar and unfamiliar people, handles unpredictable situations **Control of anxiety:** Normal range of emotions, controls emotions in all situations **Ability to show initiative and make an effort:** Shows initiative in all situations, sustains maximum effort to reach long term goals **Personal management:** Independent in BADL's, independent in IADL's **Social ability:** Appropriate with familiar and unfamiliar people, forms relationships independently **Work ability:** Open labour market **Constructive use of free time:** Constructive

Following the finalisation of the themes as seen in Table 5.1 above, the researcher translated these themes and their corresponding substantiating codes into the domain descriptors required for the outcome measure. This was an academic and theoretical exercise, done by reviewing literature on the recovery of patients following an ABI,[56-57,78] as well as literature already developed on the VdTMoCA.[8,53] It was found that the data provided by the research participants was in line with international literature on the recovery of patients following an ABI.

5.2.2 Conclusion: Objective two

As stated in Section 5.1, the second objective was also an academic and theoretic exercise, entailing the design and development of a user-friendly outcome measure using the information gathered in the first objective. In order to meet this objective, the researcher reviewed literature on the outcome measures and assessment tools based on the VdTMoCA currently available for use in psychiatric and paediatric occupational therapy.[8,29,51,75] The researcher also analysed the intended purpose of the outcome measure being developed to ensure that the design remained in line with this purpose. During this process, the measure was named the Motivation and Action in Neurological Rehabilitation Outcome Measure (MANROM). The MANROM

was developed as an outcome measure to be used in the initial as well as follow up assessments of patients following an ABI, in order to record the progress made in therapy, as well as guide the handling and presentation during treatment and assist with discharge planning. It is intended for daily, weekly or regular use and therefore is required to be quick and easy to administer or score.

The measures and tools reviewed in order to design the outcome measure include the APOM,[29] CPA,[51] FLOM[75] and OTCAP[8] and can be found in Section 4.12. The finalised framework designed for the MANROM can be found in Annexure F and a copy of the finalised MANROM, including the domain descriptors can be found in Annexure H.

5.3 Reflecting on the study

5.3.1 Limitations

This study was limited to the views, perceptions and practices of occupational therapists working in neurological rehabilitation settings within Gauteng Province, South Africa. Despite there being a few participants that studied at universities outside of the province, the vast majority of the participants studied at the two universities that offer undergraduate occupational therapy in Gauteng Province, namely the University of Pretoria and the University of Witswatersrand. A broader sample incorporating therapists working in other provinces may have brought about more discussion during the focus groups and resulted in more comprehensive data. Despite this, each focus group did have participants from different universities that attended and therefore diversity was ensured as far as possible.

There were complaints from some of the participants that the focus groups were too long. This could have been avoided by holding each focus group across two days, where the first three levels were discussed on one day, followed by the last three on the next day.

While analysing the data, the researcher realised that some of the participants offered information that was not in line with the VdTMoCA, or not applicable to the level of functioning being discussed. It was therefore speculated that having merely undergraduate exposure to the VdTMoCA may not have been sufficient to provide

insightful deductions regarding the presentation of neurological patients on different levels of Creative Ability.

During the analysis of the focus group data, it was also found that not all the domains for all the levels reached data saturation. This was noted when only one or two groups mentioned specific facts and this was not carried over in at least three groups. It was noted that “Relational contact with the body” and “Work ability” were two domains that occasionally did not reach saturation. This could be due to “Relational contact with the body” being a newly included domain specific to neurology. It may therefore require further defining and researching to determine its boundaries as well as the presentation of patients on each level in this regard. The reason for the differing views in “Work ability” could be due to the fact that the participants of the study were not specifically trained in the field of vocational rehabilitation. It could also be due to the fact that some participants were only exposed to the VdTMoCA at undergraduate level and therefore not necessarily acutely aware of du Toit’s research on the vocational potential of patients on the different levels.[8]

5.3.2 Strengths

The study possesses the following strengths:

- Experts in the field of neurological occupational therapy were included in the focus groups.
- It is recommended that three to four focus groups be held in order to reach data saturation. During this study, four groups were held.
- It is also recommended that focus groups have between four and eight participants in each and this was achieved in all four focus groups.
- The researcher is experienced in the field of neurology and ensured that the findings of the research were trustworthy. Refer to Annexure C for the Vignette of the researcher.
- The trustworthiness of the data and the measure was further enhanced through the use of an independent coder, who is an expert in the field of neurological occupational therapy as well as the VdTMoCA.
- The objectives set out at the beginning of the research process were met.

- The data was triangulated throughout the study.
- The researcher was fully immersed in the study, involved throughout the research process.
- It was found that literature supported the findings of this study as discussed in Chapter 4.

5.3.3 Researcher's personal reflection

The words of Ryan Holiday[81] rang true to the researcher throughout the research process. He stated "Writing the perfect paper is like a military operation. It takes discipline, foresight, research, strategy and, if done right, ends in total victory".[81] There were many times during the research process that the researcher felt the weight of this military operation, but persistence and strategy allowed the researcher to push through the battle and enjoy the victory in the end. This victory was felt with the drafting of the final outcome measure and the excitement of professionals to see the measure.

The study started off with an enthusiastic researcher and what was thought to be eager participants. The researcher however soon realised that despite the eagerness of occupational therapists to have the outcome measure for use in practice, this eagerness did not extend into the willingness to participate in focus groups. The researcher therefore found it difficult and quite disheartening to find participants willing to attend focus groups.

This obstacle was overcome relatively slowly, as only two focus groups were initially scheduled, with eager participants. This improved the morale of the researcher considerably to see the enthusiasm and excitement of clinicians for the publication of the measure. During the analysis of these two groups, the researcher discovered that data saturation was not reached and therefore two more groups would need to be arranged – one to possibly reach the desired saturation and the last one to prove this saturation.

The process of recruiting participants was once again a tedious one, although as seen previously, once overcome, brought a further 10 eager participants to two separate focus groups. Once the data was collected, the researcher's enthusiasm

expanded, in the anticipation of analysing the data and ultimately developing the outcome measure. As in the military operation, the researcher could see the victory; all that stood in the way of this victory was strategy and perseverance.

The analysis of the focus groups data was a smooth and enjoyable process. The researcher was surprised to find some of the insights that the participants provided and enjoyed piecing together all the information to form the outcome measure. The insights provided by the independent coder – an expert in the field of neurological occupational therapy as well as in the VdTMoCA, rounded the data off and provided the researcher with clarity and further understanding of the VdTMoCA and neurology.

The next step was an academic and theoretical process that proved insightful. The researcher used literature available on the VdTMoCA[8,53] and the recovery of patients following an ABI[54-57] to determine the validity of the data collected in the focus groups. During this stage, the researcher also used this literature to assist in the translation of the themes and substantiating codes, into domain descriptors to be included in the outcome measure. The researcher enthusiastically discovered that the data collected was in line with the VdTMoCA as well as in line with information regarding the recovery of patients following an ABI.

The final step was to meet the second objective of this study, namely design and develop a user-friendly outcome measure into which the domain descriptors could be placed. This was also an academic and theoretical process, which occurred smoothly. It was found that the research already conducted on the VdTMoCA in the field of psychiatric and paediatrics, by Casteleijn,[29] du Toit[8] and van den Reyden[29,50] provided a strong platform on which to base the framework for the MANROM.

It was when the domain descriptors were placed into the framework mentioned above, that the researcher experienced the total victory described by Holiday.[81]

Vona du Toit's Model of Creative Ability proved to be an excellent theoretical framework to use in the determination of the motivation and action of patients following an ABI.[8,53] Many occupational therapists working in neurology make use of the VdTMoCA during assessment and treatment, despite the lack of a neurology-specific outcome measure or assessment tool. This leads to a variety of differing

opinions and deductions and therefore such information cannot be used to indicate the effect of occupational therapy intervention and can also not be carried over between therapists. The VdTMoCA is taught at the majority of universities in South Africa[29] and is fast growing and being adopted by more. It is therefore embedded in the clinical reasoning of occupational therapists in South Africa and an appropriate model to be expanded into more fields of occupational therapy, through research.

As stated by Casteleijn[29] during the development of the APOM, it is of utmost importance for researchers and clinicians to acknowledge the link between clinical relevance and rigorous research methods. By combining these two elements, benefit for the patient and improved service delivery can be ensured. Research in occupational therapy can only be justified if the patients benefit from the outcome. For this reason, it is vital that the MANROM undergo further testing for its psychometric properties and clinical relevance so that is can be put into practice and benefit patients following an ABI.

Lakeman[82] indicated that an outcome measure may take up to five years to develop. It took Casteleijn five years to develop and test the psychometric properties of the APOM and it continues to undergo further testing to improve its validity.[29] The Assessment of Motor and Process Skills developed by Fischer has undergone a number of changes since its development in 1990.[29] The above mentioned information therefore indicates that assessment tools and outcome measures take time and require refinement and continuous research in order to deem them relevant and feasible. The MANROM is far from complete, requiring the assessment of its psychometric properties and appropriate implementation in practice. The researcher is therefore committed to ensure that the MANROM become a relevant and effective outcome measure for the neurological rehabilitation setting. A number of recommendations regarding the use of the measure as well as future research are suggested in order to refine this valuable measure.

5.4 Recommendations for use of the MANROM

The researcher developed the following recommendations, in accordance with the reviewed literature and the results obtained in this study, to guide occupational therapists in the use of the MANROM.

5.4.1 When to administer the MANROM

During the first step of the occupational therapy process, the occupational therapist is required to develop an occupational profile of the patient as well as conduct an analysis of their occupational performance.[2] The MANROM therefore constitutes the second phase of the evaluation (analysis of occupational performance). The MANROM should therefore be administered during the initial evaluation, prior to the commencement of treatment, in conjunction with an occupational profile (i.e. an interview schedule and obtaining collateral information). The MANROM can also be conducted in conjunction with other measurable assessment methods, such as Range of Motion testing, spasticity testing, balance assessments etc.

5.4.2 Where to administer the MANROM

As the MANROM focuses mainly on the patient's participation in occupations, it can be administered by observing the patient during basic daily functioning (within the ward, at home or in a therapy gym). It is important that the environment be as familiar and appropriate for the task at hand as possible, to ensure that environmental aspects do not influence the patient's performance (especially for the lower levels of Creative Ability). Assessments using the MANROM may take place over a few sessions, while observing the patient during task participation.

5.4.3 How to administer the MANROM

As mentioned above, the MANROM should be administered in conjunction with an interview and with the obtaining of collateral and medical information. The MANROM predominantly consists of observation of the patient during task participation. The MANROM can be used during the initial evaluation, when the patient is participating in a task. During participation in occupations, the therapist will observe and deduct information from the patient's handling of tools, handling of the social world, initiative etc., as per the MANROM. The therapist then ticks or marks off the specific domain descriptor for each domain and performance area that matches the patient's performance. Refer to Table 5.2 for an example of the scoring of the MANROM.

5.4.4 How to score the MANROM

Once the therapist has ticked or marked off the level of Creative Ability that the patient falls under for each domain and performance area, the marks/ticks are tallied up to determine which level of Creative Ability the patient is functioning on, as can be seen in Table 5.2. This therefore means that patients could function on a different level in different domains or performance areas, however the score indicates the level which the patient is predominantly functioning on.

5.4.5 When to re-administer the MANROM

The MANROM can be re-administered on a weekly basis to measure the progress of their motivation and subsequent action. This can then be included in weekly progress reports. The MANROM could also be re-administered for the second time upon discharge from hospital to indicate the level on which the patient is being discharged, for assistance with discharge planning.

5.4.6 Interpretation of the results obtained from the MANROM

The results obtained from the different administrations of the MANROM can be transcribed into a summarised scoring sheet for comparison between administrations. These results can be read vertically and horizontally. When comparing the results vertically, the change in the patient's overall level of Creative Ability can be compared to indicate improvement or regression. This result will provide the therapist with valuable information regarding the patient's overall level of Creative Ability and therefore guide the therapist in activity selection, presentation principles and handling techniques. If the results are compared horizontally, the therapist is able to track and compare the improvement in each specific domain or performance area over a period of time. This comparison will provide the therapist and family with important information on each area of the patient's life and therefore assist with discharge planning and planning for the future (return to work, the need for constant supervision or routine etc.). Table 5.3 provides an example of the summarised results and comparison sheet.

Table 5.2: Example of the scoring of the MANROM

Performance areas	Tone	Self-differentiation	Self-presentation	Participation		
				Passive	Imitative	Active
Personal management	**Totally dependent**	**Dependent** (unable to initiate, poor awareness of the need to perform self-care tasks)  **Able to participate with maximum facilitation** (1 step)	**Dependent, aware of norms** (actively involved in BADL's with prompting and set-up) **Responds better to a routine** (managed for them, improved execution)	**Participates independently in BADL's within a routine, with set-up** (poor quality, aware of norms, not compliant) **Starting simple IADL's with prompting and set-up** (better with a routine)	**Independent** (showing personal style) **Starting with IADL's**	**Independent** (good quality) **Independent in IADL's** (personal affairs)
Social ability	**None**	**Egocentric** (not reciprocal, based on own needs) **Able to recognise familiar people** (turn towards familiar people)	**One on one** (functions in parallel to others) **Dependent on others. Poor compliance with social norms/cues** (unable to initiate, unable to differentiate behaviour between known and unknown)	**Able to interact with set-up** (starts to make friends in the ward, able to follow basic conversation) **Can be included in groups** (participates passively, task-orientated)	**Reciprocal** (shows interest in others, able to interact with familiar and unfamiliar) **Want to interact** (want to be part of a community, others must initiate or set-up the interaction)	**Appropriate with familiar and unfamiliar people** **Forms relationships independently**
Work ability	**None**	**None** 	**Sheltered** (repetitive, constant supervision, demonstration, low production, less than 50%)	**Sheltered** (routine, repetitive, will follow job description, supervision required)	**Open labour market** (reasonable accommodations, work dependent, predictable, able to meet job description – no extra). **Able to study**	**Open labour market** (supervisory or managerial positions, suggests own reasonable accommodations, occupation dependent, works towards a promotion/improving self) **Able to study**
Constructive use of free time	**None**	**None** 	**Passive** (facilitated by others, sleep)	**Passive** (requires prompting, TV)	**Will participate in meaningful tasks** (independent with set-up, not competitive)	**Constructive** (explores new tasks, aware of the benefit of leisure, adapts tasks to suit physical abilities)
TOTAL	**0**	3	**1**	**0**	**0**	**0**
LEVEL	**SELF-DIFFERENTIATION**					

Table 5.3: Example of the MANROM scoring sheet for comparison

	Date: 01-09-2018	**Date:**	**Date:**	**Date:**
Motivation	Self-Differentiation			
Action	Self-Differentiation			
Quality of product or performance and task concept	Self-Presentation			
Relational contact with the body	Self-Differentiation			
Relational contact with the social world	Self-Presentation			
Relational contact with tools and materials	Self-Presentation			
Control of anxiety	Self-Differentiation			
Ability to show initiative and make an effort	Self-Presentation			
Personal management	Self-Differentiation			
Social ability	Self-Presentation			
Work ability	Self-Differentiation			
Constructive use of free time	Self-Differentiation			
RESULT	Self-Differentiation			

5.5 Recommendations for future research

The development of an outcome measure cannot be finalised after one study. Several improvements and adjustments on the measure are possible. The MANROM is in an early stage of development, therefore recommendations are provided below to optimise it as a relevant measure.

5.5.1 Validity

5.5.1.1 Content validity

The first of the three validity assessments required for the testing of the psychometric properties of the MANROM, is content validity. Content validity is generally performed by experts on the subject matter in question, where the information is scrutinized for the relevance of the data to the study/measure.[83]

In order to determine the content validity of the MANROM, it is suggested that two indices of content validity be tested.[83] The first index is the Item-level content validity. This would involve determining the validity of the individual domain descriptors. The second index is the Scale-level Content Validity Index, which determines the validity of all the data within the outcome measure as a whole.[83] Research by Polit and Beck[61] and Lynn[83] report on the indices required per number of participants in the content validity assessment.

There are different methods that can be used when testing content validity. An example of one is the Delphi methods.[84] The Delphi method is defined by Keeney et al[85] as “a multi-staged survey which attempts ultimately to achieve consensus on an important issue”. The method consists of three rounds, where participants are required to vote on the appropriateness of items in a measure (participants are not required to sit together to do this, but are rather sent the questionnaire via email or the post). After the first round, the measure is adjusted in accordance with the votes and resent to the participants for voting. This is continued a third time.[85]

Alternatively, a rating scale with one round can be used, where participants are required to vote on the relevancy of the information in the measure. Table 5.4 below provides an example of such a rating scale. This method also does not require participants to attend a group, but rather answer a questionnaire sent via email or the post.[29]

Table 5.4: A rating scale for content validity

Rating	Description	
1	The item fits the domain and performance are very poorly	Irrelevant
2	The item fits the domain and performance are poorly	
3	The item fits the domain and performance are moderately	Relevant
4	The item fits the domain and performance are well	
5	The item fits the domain and performance are very well	

For both of the above mentioned methods, statistical analysis should be conducted in order to determine the relevance of the items in the measure and the measure then adjusted accordingly.

5.5.1.2 Construct validity

Due to the MANROM being a novel measure, the analytic statistics will be naïve, because the information that will be developed regarding its psychometric properties currently does not exist. Despite this, it is still important to assess the construct validity of the MANROM as this information will add to the progression of the measure into a valid and reliable outcome measure.

One recommendation regarding the assessment of the construct validity of the MANROM is by therapists assessing patients following an ABI, using the MANROM. The data should then be converted to numerics and a correlation matrix drawn using the Pearson correlation coefficient, according to the domains of the MANROM. The correlation between different domains and performance areas can then be drawn in an attempt to initiate the process of proving that the MANROM measures what it purports to measure.[29]

5.5.1.3 Ecological validity

As mentioned in the literature study in Chapter 2, the core focus of any occupational therapy assessment and treatment is the enhancement of a patient's occupational performance in daily life.[2] This therefore means that the assessment of the ecological validity of the MANROM is of utmost importance to ensure that the measure remains in line with the core focus of occupational therapy. Ecological validity is the relationship between the results obtained in an experimental situation (during

assessment in therapy) versus the results obtained in natural, everyday situations (at home). This relationship is determined through the reflection of the patient or a significant other on their satisfaction with their real life performance in relevant and meaningful occupations.[29,84,86-87]

To conduct this ecological validity assessment, questionnaires can be given to patients or significant others. For the patient to fill in the questionnaire independently, it is important that the patient present with sound cognitive abilities, being able to understand and accurately indicate the satisfaction with his or her performance. For a significant other to fill in the questionnaire, it is important that the person be present during the patient's participation in meaningful occupations, within their home environment.[29]

In order to determine which questionnaire is appropriate for use, the researcher should discuss a number of questionnaires with patients who have suffered an ABI that present with sound cognition in order to obtain their views on the relevance of the questions. A number of patient satisfaction questionnaires are available, including Treatment Perception Questionnaire,[88] the Canadian Occupational Performance Measure[26] and the Pre-discharge Assessment Tool,[29,89] to name a few.

5.5.2 Reliability

It is recommended that the MANROM undergo two reliability assessments, namely an assessment for the inter-rater reliability and an assessment for the intra-rater reliability of the measure. According to Polgar and Thomas,[90] inter-rater reliability is when different therapists or raters use the same measure in order to measure the same phenomenon or symptoms at the same time. On the other hand, intra-rater reliability is the correlation between a number of ratings done by one therapist or rater. Reliability therefore can be defined as measuring the reproducibility of a measure.[29,90] In terms of the MANROM, this is an important property to assess, as the measure will be used on the same patient at least twice and if the measure is not reliable, the incorrect information could be used when making important decisions regarding the patient's progress in therapy. A discussion of some of the methods that can be used to assess the inter-rater and intra-rater reliability of the MANROM is provided below.

5.5.2.1 Inter-rater reliability

To conduct an inter-rater reliability assessment, different therapists or raters should rate the same patient who is known to all of them, using the MANROM. These therapists should all rate the patient twice, a few months apart (time period can be determined by the researcher and statistician). The scores of these assessments should then be converted to numerical figures and the medians of each domain calculated for each rater. The average of the median per domain should then be calculated.[29]

There are a number of different methods that can be used to calculate the inter-rater reliability of a measure, one of these being the Kruskal-Wallis one-way analysis of variance test.[91] This particular method is sensitive to differences in central tendency and therefore tests data for the presence of significant differences.[29,91]

5.5.2.2 Intra-rater reliability

The intra-rater reliability of the MANROM can be assessed using the same data generated from the assessment of the inter-rater reliability. This can be done by comparing each individual rater's first and second scores, rather than comparing scores between raters. This is done in order to determine the consistency of each rater's assessment of the patient over a period of time.

Again, there are a number of different methods that can be used to calculate the intra-rater reliability of a measure, one of these being Spearman's correlation coefficients.[29]

5.5.3 Internal consistency

It is further recommended that the internal consistency of the MANROM be assessed, to further improve the psychometric properties of the measure. Internal consistency refers to the consistency among individual items in a scale and thereby refers to if a patient responds consistently to items within a measure.[29]

To conduct an internal consistency assessment, researchers should assess how well individual domain descriptors in the MANROM correlate with the sum of the residual domains and levels of Creative Ability.

One method suggested for assessing the internal consistency of a measure is the Cronbach's Alpha Index Test.[92] This test assesses the internal consistency of a measure by calculating the correlation coefficient. A correlation of 0.7 or above is an indication of acceptable internal consistency. Correlations of above 0.9 could indicate items that are redundant.[29,92]

5.5.4 Sensitivity

It is also recommended that the MANROM be assessed for sensitivity. The assessment of sensitivity is important in order to detect change in the patient's motivation and action between base-line and follow-up assessments.[29]

To conduct a sensitivity assessment, it is recommended that therapists assess a number of patients at two data collection points, namely the base-line and final assessments. The data obtained for each patient should include both the base-line and final result. Intervention can occur in between the two data collection points.[29]

One of the recommended methods of assessing sensitivity is with the use of the t-test for the paired observations.[29] Due to intervention occurring between the two data collection points, change in a positive direction between the initial and final measure could be viewed as positive and indicative of improvement in function. The larger the number of participants (patients), the more reliable the sensitivity result will be.[29]

5.5.5 Development of treatment principles

The Occupational Therapy Creative Ability Programme (OTCAP) mentioned in Chapter 2 that was developed by du Toit, includes treatment aims and methods recommended per level of Creative Ability.[8]

The treatment aims in the OTCAP include aspects of each domain that require attention on each level of Creative Ability. For the OTCAP, this includes; motivation, action, quality of product, relational contact with materials objects, relational contact with people, relational contact with situations, control of anxiety, ability to demonstrate initiative and ability to make an effort.[8]

The “method of presenting treatment” in the OTCAP includes recommendations regarding the following[8]:

- The set-up of the treatment area
- The therapists approach or presentation principles
- The method
- Motivation
- Presentation principles regarding level-appropriate action and handling of materials
- Other specific recommendations per level of Creative Ability (e.g. work habits on Passive Participation etc.)

It is therefore recommended that future studies on motivation and action in neurological rehabilitation include the determination of treatment and presentation principles for the different levels of Creative Ability for patients following an ABI. This information can be obtained through focus groups with experts in the field, focus groups with patients who have suffered an ABI, as well as through recording of intervention with patients following an ABI who have been assessed with the MANROM.

5.6 Conclusion

The researcher set out to address a gap in neurological occupational therapy – the lack of an outcome measure based on motivation and action. This intention resulted in the development of an outcome measure for occupational therapists in neurological rehabilitation, namely the Motivation and Action in Neurological Rehabilitation Outcome Measure (MANROM).

The first objective of this study was to determine the domain descriptors for the first six levels of Creative Ability, to be included in the outcome measure. The participants included occupational therapists currently practicing or lecturing in neurology. The focus groups provided the researcher with data that was transcribed verbatim and analysed for themes and codes and reviewed by an independent coder. These themes and codes were translated into domain descriptors in an academic and theoretical process that involved the review of literature available on the VdTMoCA and the recovery of patients following an ABI. The second and final objective of the

study was also an academic and theoretical process, where the researcher designed and developed a user-friendly framework for the domain descriptors to fit into.

Psychometric properties of the MANROM need to be tested to prove its validity, reliability, consistency and sensitivity.

The journey of the development of the MANROM is not complete and the researcher looks forward to continuing with research on this measure and following through on the recommendations made in this study. The researcher believes that the MANROM will provide valuable contributions to the field of neurological rehabilitation and therefore ultimately improve the care and recovery of patients following an acquired brain injury.

REFERENCES

1. Casteleijn D. Using measurement principles to confirm the levels of creative ability as described in the Vona du Toit model of creative ability. S Afr J Occup Ther. 2014; 44(1).
2. American occupational therapy association. Occupationl therapy practice framework: Domain and process 3rd edition. Am J Occup Ther. 2014; 37(6):1489-9.
3. Jacobs K, Jacobs L. Quick reference dictionary for occupational therapy. 4th ed. Thorofare: Slack Incorporated 2004.
4. Kat L, Schipper K, Knibbe L, Abma T. A patient's journey: Acquired brain injury. Br Med J. 2010 May; 340(7754):1029-30.
5. Barnes M. Principles of neurological rehabilitation J. Neurol. Neurosurg. Psychiatry. 2004; 4.
6. Law M, Baum C. Measuring occupational performance - supporting best practice in occupational therapy. In: Law M, Baum C, Dunn W, editors. Measurement in occupational therapy. New York: Slack Incorporated. p. 4-19.
7. Collins concise dictionary. Glasgow 2004. p. 1037.
8. du Toit V. Patient volition and action in occupational therapy. Pretoria, South Africa: the Vona & Marie du Toit Foundation; 2009.
9. Casteleijn D. The use of core concepts and terminology in South Africa. World Federation of Occupational Therapists Bulletin 2012.
10. Hargreaves W, Shumway M, Hu T, Cuffel. Measuring mental health outcomes, Cost outcome methods. London: Academic Press; 1998.
11. Casteleijn D. Stepping stones from input to outcomes: An occupational perspective. S Afr J Occup Ther. 2013 Apr; 43(1).
12. Bond T, Fox C. Applying the Rasch model: Fundamental measurement in the human science. Mahwah: NJ: Lawrence Erlbaum Associates, 2007.
13. Tennant A, Conaghan P. The Rasch measurement model in rheumatology: What is it and why use it? When should it be applied, and what should one look for in a Rasch paper? Arthritis Rheumatology. 2007; 57(8):1358-62.

14. Iramaneerat C, Smith E, Smith R. An introduction to Rasch measurement. In: Osbourne J, editor. Best practice in quantitative methods. Los Angeles: Sage Publications, Inc; 2008. p. 50-69.
15. Hagquist C, Bruce M, Gustavsson J. Using the Rasch model in nursing research: an introduction and illustrative example. Int Journal of Nurs Stud. 2009; 46:380-93.
16. Clarke V, Braun V. Using thematic analysis in psychology. Qualitative research. 2006; 3(2):102.
17. Townsend E WA. Occupational justice. In: Christiansen CH TE, editor. Introduction to occupation: the art of science and living. Upper Saddle River, NJ: Prentice Hall. 2004. p. 243-73.
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. Robinson R, Kubos K, Starr L. Mood disorders in stroke patients. Brain. 1984; 107:81-93.
20. Bosman H, cvan Heugten C, Winkens I, Smeets S, Visser-Meily J. Further validation of the motivation for traumatic brain injury rehabilitation questions (MOT-Q) in patients with acquired brain injury. Neuropsychol Rehabil. 2016; 26(1):87-102.
21. Eccles J WA. Motivational beliefs, values and goals. Annu Rev. Psychol. 2002; 53(109-32).
22. Maclean N, Pound P. A critical review of the concept of patient motivation in the literature on physical rehabilitation. Soc Sci and Med. 2000; 50:495-506.
23. O'Gorman G. Anti-motivation. Physiotherapy. 1975; 61:176-9.
24. Maclean N, Pound P, Wolfe C, Rudd A. The concept of patient motivation. Stroke. 2002; 33:444-8.
25. Wilcock A. A theory of the human need for existence. J Occup Sci. 1993; 1(1).
26. Law M, Baptiste S, Carswell A, McColl M, Polatajko H, Pollock N. Canadian occupational performance measure. 3rd ed. Canada: CAOT Publlications Ace.; 1998.

27. Krupa T, Fossey E, Anthony W, Brown C, Pitts D. Doing daily life: How Occupational therapy can inform psychiatric rehabilitation practice. Psychiatr Rehabil J. 2009; 32(3):155-61.
28. McBean D, van Wijck F. Applied neuroscience for all allied health professions: Churchill Livingstone; 2012.
29. Casteleijn J. Development of an outcome measure for occupational therapists in mental health care settings. IOS Press. South Africa: University of Pretoria; 2010.
30. Vosloo J. A sport management programme for educator training in accordance with the diverse needs of South African schools. South Africa: North-West University; 2014. p. 299-353.
31. Klopper H. The qualitative research proposal. South Africa: North-West University; 2008.
32. de Vos A, Strydom H, Fouche C, Delport C. Research at grass roots. 4th ed. South Africa, Pretoria: Van Schaik; 2011.
33. Denzin N, Lincoln Y. Sage handbooks of qualitative research. London: Sage; 1994, 2000, 2005, 2011.
34. Randolph J. A guide to writing the dissertation literature review. Practical assessment, research & evaluation. 2009; 14(13):1-13.
35. Creative commons attribution [Internet] Model of creative ability. Cape Town: Matuma Ramafikeng; 2009 [updated 2009; cited 2017 Feb 18]. Available from: www.oerafrica.org>FTPFolder>pdf.
36. Gainotti G. Emotional behaviour and hemispheric side of lesion. Cortex. 1972; 8:41-55.
37. Denes G, Semenza E, Lis A. Unilateral spatial neglect and recovery from hemiplegia. Brain. 1982; 105:543-52.
38. Lily R, Cummings J, Benson D. The human Kluver-Bucy syndrome. Neurology 1983; 33:1141-5.
39. Roberts S, Marin MD. Differential diagnosis and classification of apathy. Am J Psychiatry. 1990; 147:22-30.
40. Mahoney F, Barthel D. Functional evaluation: The Barthel index. Md Med J. 1965; 14(1):56-61.

41. Shah S, Vanclay F, Cooper B. Improving the sensitivity of the Barthel index for stroke rehabilitation. J Clin Epidemiol. 1989; 42(8):703-9.
42. Chard G. An investigation into the use of the assessment of motor and process skills (AMPS) in clinical practice. Br J Occup Ther. 2000; 63(10):481-8.
43. WHO. International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of diseases, published in accordance with resolution WHA29.35 of the twenty-ninth world health assembly. Geneva: World health organisation; 1980.
44. Wright K [Internet] Introduction to the disability rating scale. Santa Clara Valley: The centre for outcome measurement in brain injury; [updated 2000; cited 2018 Jun 20]. Available from: http://www.tbims.org/combi/drs/index.html.
45. Turner-Stoke L [Internet] The UK FIM+FAM (functional assessment measure). Middlesex [updated 2012 Sept; cited 2018 Jun]. Available from: https://www.kcl.ac.uk/nursing/departments/cicelysaunders/resources/FIMFAM-manual-v2.2-Sept-2012-print-double-sided.pdf.
46. Malec J [Internet] Manual for the Mayo-Portland adaptability inventory (MPAI-4). Indiana [updated 2008 Jan; cited 2018 Jun 14]. Available from: http://www.tbims.org/combi/mpai/manual.pdf.
47. Marequez de la Plata C, Qualls D, Plenger P, Malec J, Mayden M. Ecologically relevant outcome measure for post-inpatient rehabilitation. Neuropsychol Rehabil. 2017; 40:187-94.
48. Kramer K, Kielhofner G, Lee S, Ashpole E, Castle L. Utility of the model of human occupation screening tool for detecting client change. Occup Ther Ment Health. 2009; 25:181-91.
49. Perry A, Morris M, Unsworth C, Duckett S, Skeat J, Dodd K, et al. Therapy outcome measures for allied health practitioners in Australia: the AusTOMs. International Journal for Quality in Health Care. 2004; 16(4):285-91.
50. VdTMoCAF-UK [Internet] Assessment tools. UK: VdT MoCA foundation (UK. [updated 2018; cited 2018 Jun 14]. Available from: Available: http://www.vdtmocaf-uk.com/page/assessment-tools-and-outcome-measures.

51. Casteleijn D, Smit C. The psychometric properties of the creative participation assessment. SAJOT. 2002; 32(1):6-11.
52. Casteleijn D, Zietsman K, Crawford S, Grahan-Parker L, Karadimos L, Michell S. The psychometric properties of the functional levels outcome measure (FLOM): Construct validity, internal consistency and inter-rater reliability. Research project in partial fulfilment of the requirements for BSc IV OT (WITS)2013.
53. de Witt P. Creative ability, a model for psychiatric occupational therapy. In: Crouch R, Alers A, editors. Occupational therapy in psychiatry and mental health. 4th ed. Johannesburg: Maskew Miller Longman; 2005.
54. Giancino J, Fins J, Laureys S, Schiff N. Disorders of consciousness after acquired brain injury: the state of the science. Nat Rev Neurol. 2014; 10(1038).
55. Lin K, Dulebohn S. Rancho Los Amigos: StatPearls Publising LLC; 2018.
56. Brainline [Internet] What is the Glasgow coma scale? [updated 2018, Feb 13]. Available from: https://www.brainline.org/article/what-glasgow-coma-scale.
57. McLeod S [Internet] Maslow's hierarchy of needs. 2018 [updated 2018, May 21]. Available from: https://www.simplypsychology.org/maslow.html.
58. Synapse [Internet] Some of the main difficulties that can affect people after brain injury - fact sheet. Australia. 2018 [cited 2018 Nov 15]. Available from: http://synapse.org.au/information-services/some-of-the-main-difficulties-that-can-affect-people-after-brain-injury.aspx.
59. Mason J. Qualitative researching. 2nd ed. London: SAGE publications;
60. Lambert V, Lambert C. Qualitative descriptive research: an acceptable design. Pacific Rim Int J Nurs Res. 2012 Oct-Dec; 16(4):255-6.
61. Polit D, Beck C. Nursing research: generating and assessing evidence for nursing practice. 2nd ed. Philadelphia: Lippencott, Williams and Wilkens; 2008.
62. Breytenbach F. Content validity of the modified Barthel index for stroke patients in South Africa [dissertation]. Johannesburg: University of Witswatersrand; 2016.

63. Freeme J. The training and practice in neurological rehabilitation theories in the occupational therapy management of stroke patients in South Africa [dissertation]. Johannesburg: University of Witswatersrand; 2011.
64. Evalumed [Internet] Reasons for using focus groups. Leeds [updated 2011; cited 2017 Mar 29]. Available from: www.evalued.bcu.ac.uk/tutorial/4b.htm.
65. Clarke V, Braun V. Thematic analysis. In: Michalos A, editor. Encyclopaedia of quality of life and well-being research. Netherlands: Springer; 2014. p. 6626-8.
66. Willig C. Introducing qualitative research in psychology. 3rd ed. Berkshire: McGraw-Hill education; 2013.
67. Smith J, Osborn M. Qualitative psychology. In: Smith J, Osborn M, editors. Interpretative phenomenological analysis. Birkbeck College: SAGE publishing; 2015. p. 55-80.
68. Maguire M, Dalahunt B. Doing a thematic analysis: a practical, step-by-step guide for learning and teaching scholars. AISHE-J. 2017 Autumn; 3:3351-9.
69. Krefting L. Rigor in qualitative research: the assessment of trustworthiness. Am J Occup Ther. 1991; 45(3):214-22.
70. Anthony J, Onwuegbuzie A, Leech N. Validity and qualitative research: an oxymoron? Quality & quantity. 41:233-49.
71. Cochrane T, Williams M [Internet] Disorders of conciousness: Brain death, coma and the vegetative and minimally conscious states. Dana; 2015 [updated 2015 Feb 4; cited 2018 Sept 16]. Available from: http://www.dana.org/Publications/ReportOnProgress/Disorders_of_Consciousness__Brain_Death,_Coma,_and_the_Vegetative_and_Minimally_Conscious_States/.
72. Cicerone K, Levin H, Malec J, Donald S, Whyte J. Cognitive rehabilitation interventions for executive function: moving from bench to bedside in patients with traumatic brain injury. J Cog Neurosci. 2006; 18(7):1212-22.
73. Brink H, van der Walt C, van Rensburg G. Fundamentals of research methodology for health care professionals. South Africa: Juta; 2006.
74. Ramano E. Perceptions and practices of occupational therapists in determining work capacity of employees suffering from major depressive disorder. Pretoria: University of Pretoria; 2011.

75. Casteleijn D, Zietsman K, Crawford S, Grahan-Parker L, Karadimos L, Mitchell S. The psychometric properties of the functional levels outcome measure (FLOM): Construct validity, internal consistency and inter-rater reliability. Research project in partial fulfillment of the requirements for BSc IV OT (WITS). Unpublished document; 2013.
76. de Bruyn J. Discussion about the definition of neurology-specific domains and performance areas. 2018.
77. SAHealth [Internet] Emotional disorders following brain injury. South Australia: Government of South Australia; [cited 2018 Nov 15]. Available from: https://www.sahealth.sa.gov.au/wps/wcm/connect/b86525e6-a79e-4775-8978-6a22aab95c2b/Fact+sheet+-+Emotional+disorders+following+brain+injury.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-b86525e6-a79e-4775-8978-6a22aab95c2b-msqqGXF.
78. Hagen C. The Rancho levels of cognitive functioning 3rd ed. Rancho Los Amigos medical center 1998.
79. [Internet] Egocentric. 2018. Available from: https://dictionary.cambridge.org/dictionary/english/egocentric.
80. Greenbaum T. The handbook for focus group research. Thousand Oaks: Sage Publications Inc.; 1998.
81. Holiday R [Internet] Ryan Holiday Quotes. [cited 2018 Oct 10]. Available from: https://www.brainyquote.com/authors/ryan_holiday.
82. Lakeman R. Standardized routine outcome measurement: Pot holes in the road to recovery. Int Journal of Mental Health Nurs. 2004; 13:210-5.
83. Lynn M. Determination and quantification of content validity. Nursing Research. 1986; 35:382-5.
84. Kielhofner G. Research in occupational therapy: Methods of injuiry for enhancing practice. Philadelphia: FA Davis Company; 2006.
85. Keeney S, Hasson F, McKenna H. The Delphi technique in nursing and health research. West Sussex, UK: Blackwell; 2010.

86. Franzen M, Wilhelm K. Conceptual foundations of ecological validity in neuropsychological assessment. In: Sbordone R, Long C, editors. Ecological validity of neuropsychological testing. Delray Beach, FL: GR Press/St Lucie Press; 1996. p. 91-112.
87. Spooner D, Pachana N. Ecological validity in neuropsychological assessment: A case for greater consideration in research with neurologically intact populations. Archives of Clin Neuropsych. 2006; 21(327):337.
88. Marsdon J, Stewart D, Gossop M, Rolfe A, Bachus L, Griffiths P, et al. Assesing client satisfaction with treatment for substance use problems and the development of the treatment perceptions questionnaire. Addiction Research. 2000; 8(5):455-70.
89. Rudman D, Took J, Eimantas T, Hall M, Maloney K. Preliminary investigation of the content validity and clinical utility of the predischarge assessment tool. Canadian J Occ Ther. 1998; 65(1):3-11.
90. Polgar S, Thomas S. Introduction to research in the health sciences. 5th ed. London: Churchill Livingstone Elsevier; 2008.
91. Howell D. Fundamental statistics for behavioral sciences. 5th ed. London: Thomson Brooks/Cole; 2006.
92. Spiliotopoulou G. Reliability reconsidered: Cronbach's alpha and paediatric assessment in occupational therapy. Austr Occup Ther J. 2009; 56:150-5.

ANNEXURES

Annexure A

Information leaflet and informed consent for non-clinical research – focus groups

INFORMATION LEAFLET AND INFORMED CONSENT FOR NON-CLINICAL RESEARCH – FOCUS GROUPS

Title of study: Development of an Outcome Measure Based on Motivation and Action for Occupational Therapists in Neurological Rehabilitation

Dear potential participant

1) Introduction

You are invited to volunteer to participate in a research study. This information leaflet is to assist you in deciding if you would like to provide consent to participate. Before you give consent, you should fully understand what is involved. If you have any questions which are not fully answered in this leaflet, please do not hesitate to ask the researcher. You should not agree to participate unless you are completely happy about all the procedures involved.

2) The nature and purpose of this study

The purpose of this study is to develop an outcome measure for occupational therapists in the neurological rehabilitation setting, based on patients' level of motivation and action. The outcome measure will assist occupational therapists in determining the level of Creative Ability of patients with neurological conditions, as well as assist therapists in determining the change in the patients' occupational performance following treatment. The measure will provide therapists with an objective measure of the patients' level, as well as guide the therapist in level-appropriate treatment of patients, to thereby increase patient-specific treatment.

The first objective of this study is to obtain domain descriptors for each of the levels of Creative Ability which are to be included in the outcome measure.

3) Explanation of procedures to be followed

The first objective involves the use of focus groups for which CPD points will be applied. This will involve a group discussion consisting of 4 - 10 participants, all with experience in adult neurological occupational therapy, as well as exposure to the Vona du Toit Model of Creative Ability (VdTMoCA). The following steps provide a brief explanation of the process that will take place during the focus groups:

Step 1 – Introduction:

Rules for the group will be discussed, as well as introduction of all the participants present. The facilitator will provide an overview of the purpose of the group.

Step 2 – Discussion:

Each level of Creative Ability will be discussed according to the specific domain as set-out in the VdTMoCA. Each participant will be encouraged to contribute to the discussion and provide input from their experience and prior knowledge. Discussions will be moderated by the group facilitator (researcher) and continue until the group agree upon neurological-specific domain descriptors for each level discussed. The facilitator will ensure that all participants have a visual indication of the descriptions to ensure that they are able to add extra information where necessary and follow the progression of the group.

Step 3 – Closing:

The facilitator will ensure that all participants are satisfied with information to be included in the outcome measure. A summary of the information given during the focus group will be briefly given by the facilitator and participants given the chance to add further comments if necessary. Each participant will be given the opportunity to make a final closing comment as well as provide recommendations.

Please note that all focus groups will be voice recorded, as well as documented for transcription purposes.

4) Risk and discomfort involved

There are no risks or discomforts involved in participating in this study. The discussion will take one day (maximum four hours) of your time.

5) Possible benefits of the study

The outcome measure will assist occupational therapists in determining the level of Creative Ability of patients with neurological conditions, as well as assist therapists in determining the change in the patient's occupational performance following treatment. The measure will provide therapists with an objective measure of the patients' level, as well as guide the therapist in level-appropriate treatment of patients, to thereby increase patient-specific treatment.

This study will be conducted with the utmost respect to all participants and their views.

6) What are your rights as a participant?

It is important to remember that your participation in this study in entirely voluntary. You may refuse to participate or stop at any time during the focus group without giving any reason. Please be aware that your withdrawal will not affect you or the company you represent.

7) Has the study received ethical approval?

This study has received written approval from the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria. A copy of the approval letter can be made available if you wish to have a copy. Ethics Reference No: 37/2018.

Contact details:

Dr R Sommers

Deputy Chairperson: Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Tel: 012 356 3084 or 012 356 3085

8) Information and contact person

The contact person for this study is Samantha Lee. If you have any questions regarding the study please contact her on 0829431557. Alternatively, you may contact the study supervisor Mrs Jodie de Bruyn on 012 356 3222.

9) Compensation

Please remember your participation in this study is voluntary. There will be no compensation/contribution towards your transport expenses. Refreshments will be provided on the day of the focus group.

10) Confidentiality

All information that you provide during the focus group will remain strictly confidential. Once the data has been analysed, all information will remain anonymous. Any articles in journals and research reports will not include any information that may identify you.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person requesting my informed consent to participate in this study has informed me about the nature, process, discomforts, risks and benefits of this study. I also confirm that I have received; read and I understand the above given information (information leaflet and informed consent). I am aware that the results of the study as well as my personal details, will be handled anonymously during the research process. I confirm that I am participating willingly, I had time to ask any necessary questions and I have no objection to participate in this study. I also confirm that I understand that there will be no penalty should I wish to withdraw consent and discontinue with the study. I acknowledge that my withdrawal will not affect myself or the company I represent in any way. I also hereby give consent for the focus groups to be audio recorded.

Participants name: _____ (Please Print)

Participant's signature: _____ Date: _____

Researcher's name: _____ (Please Print)

Researcher's signature: _____ Date: _____

Witness's name: _____ (Please Print)

Witness's signature: _____ Date: _____

Annexure B

Participant Demographics Survey

PARTICIPANT DEMOGRAPHICS SURVEY

Please fill in the following demographics sheet. The information provided here will be kept strictly confidential.

1. Place of undergraduate study

2. Years of experience in neurology

3. Have you been exposed to the Vona du Toit Model of Creative Ability (during undergraduate or postgraduate studies). Please specify.

4. Have you attended any neurology-based courses following undergraduate studies?

Annexure C

Vignette of the Researcher

Vignette of the Researcher

Samantha Lee is an occupational therapist with four years' experience in occupational therapy. She completed her community service year at a government hospital in Kwa-Zulu Natal. During this year, she was exposed to orthopaedics and neurology in adults. Following her community service year, she started working in a private, hospital-based practice in Gauteng, where she is still employed. The practice specialises in neurology, working closely with the Neurologists and Neuro-surgeons at the hospital. Both in and out patients are seen at the practice. After one year in private practice, she also started working as a part-time lecturer at the university, supervising fourth year students in the physical block, as well as lecturing and supervising second year students in neurology.

At the start of this research project on the development of an outcome measure, the research was well acquainted with the neurological occupational therapy setting in Gauteng, especially the Pretoria area. This acquaintance happened as a result of courses as well as interest groups that are attended by many of the occupational therapists working in neurology, in Pretoria. Supervising of students at various government hospitals in Pretoria also assisted with this acquaintance.

The research idea emerged as a result of the researcher's experience while working with neurological patients. The researcher developed a strong conviction to develop an outcome measure based on motivation and action due to the lack thereof in the neurological setting. It is so evident while working hands on with patients that such an outcome measure would be able to assist in the correct grading of treatment tasks, as well as in the discharge planning. The tool would also be able to assist with motivating medical aids, families and doctors of the benefit of occupational therapy. It was this conviction that urged the researcher to start the research process.

The researcher continued working full time in private practice as well as part-time lecturing at the university during the research process. This created the opportunity for the researcher to immerse herself in the clinical situation. She was able to discuss ideas with colleagues as well as with lectures at the university and other expert occupational therapists during student supervision and at neurology interest groups. During these interactions, therapists' personal perspectives and viewpoints were often discussed.

These contact sessions with different therapists working in neurology assisted the researcher in broadening her understanding of the clinical situation and the challenges therapists face due to the lack of such tool. The advantage of this immersion is that occupational therapists did not give preferred responses during the focus groups because they knew that the researcher is familiar with the clinical situation.

This relationship that developed between the researcher and occupational therapists could have influenced the researcher's interpretations of certain situations during the research. The interpretation of the results occurred early in the research process and could therefore not be influenced much by the subjective feelings or incorrect interpretations of the researcher. The code-recode procedure, thematic analysis guidelines as well as the use of an expert reviewer also assisted in this regard.

Annexure D

Guideline for the questions used in the focus groups

Guideline for the questions used in the focus groups

Questions	Cues/Prompts
Let's talk about the first level of the outcome measure – Tone. Is there anything that stands out for you in terms of what a neurological patient on tone would present like?	• Action • Motivation • Quality of product/Task concept • Relational contact with the body • Relational contact with materials and tools • Relational contact with the social world • Control of anxiety • Ability to show initiative and make an effort • Personal management • Social ability • Work ability • Constructive use of free time
In your opinion of the second level of Creative Ability, Self-Differentiation, is there anything that stands out for you in terms of what a neurological patient on Self-Differentiation would present like?	• Action • Motivation • Quality of product/Task concept • Relational contact with the body • Relational contact with materials and tools • Relational contact with the social world • Control of anxiety • Ability to show initiative and make an effort • Personal management • Social ability • Work ability • Constructive use of free time
Let's now discuss the third level of Creative Ability – Self-Presentation. Is there anything that stands out for you in terms of what a neurological patient on Self-Presentation would present like?	• Action • Motivation • Quality of product/Task concept • Relational contact with the body • Relational contact with materials and tools • Relational contact with the social world • Control of anxiety • Ability to show initiative and make an effort • Personal management • Social ability • Work ability • Constructive use of free time

Questions	Cues/Prompts
In your opinion of the fourth level of Creative Ability, Passive Participation, is there anything that stands out for you in terms of what a neurological patient on Passive Participation would present like?	• Action • Motivation • Quality of product/Task concept • Relational contact with the body • Relational contact with materials and tools • Relational contact with the social world • Control of anxiety • Ability to show initiative and make an effort • Personal management • Social ability • Work ability • Constructive use of free time
Let's now discuss the fifth level of Creative Ability – Imitative Participation. Is there anything that stands out for you in terms of what a neurological patient on Imitative Participation would present like?	• Action • Motivation • Quality of product/Task concept • Relational contact with the body • Relational contact with materials and tools • Relational contact with the social world • Control of anxiety • Ability to show initiative and make an effort • Personal management • Social ability • Work ability • Constructive use of free time
In your opinion of the sixth level of Creative Ability, Active Participation, is there anything that stands out for you in terms of what a neurological patient on Active Participation would present like?	• Action • Motivation • Quality of product/Task concept • Relational contact with the body • Relational contact with materials and tools • Relational contact with the social world • Control of anxiety • Ability to show initiative and make an effort • Personal management • Social ability • Work ability • Constructive use of free time

Annexure E

Visual illustration used during focus groups

PowerPoint presentation used as visual illustration during focus groups

Focus Group

Development of an Outcome Measure based on Motivation and Action for Occupational Therapists in Neurological Rehabilitation

1

Overview of focus group

1) Welcoming
2) Rules
3) Recap of levels
4) Introduction, recording of ideas and discussion of each level, domains and performance areas
5) Finalisation of inclusion criteria
6) Closing

2

Rules of the group

- Respect others opinions
- Respect others chance to express their views/opinions
- One speaker at a time
- Please turn cellphones on silent

Please note that the focus group will be voice recorded for transcription purposes

3

Outline for the outcome measure

Domain	Tone	Self-differentiation	Self-presentation	Participation		
				Passive	Initiative	Active
Arousal						
Motivation						
Quality of pressure: Task strength						
Relational: person-task, the body						
Relational: person-task, materials, and tasks						
Relational: person-the social world						
Control of activity						
Safety, resilient, initiative, and motivation						

4

Outline for the outcome measure

Domain	Tone	Self-differentiation	Self-presentation	Participation		
				Passive	Initiative	Active
Personal management						
Arousal activity						
Work activity						
Communicative use of time, time						

5

Recap of levels

Level of creative ability	Summary
1) Tone	Motivation is directed at the will to live (biological systems). Defenceless, dependent and incapable.
2) Self-differentiation	Establishing and maintaining self-awareness as a separate entity from the environment, objects and people in it. **Destructive action** The most primitive interaction they have with the world. Destructive action aims to define their body boundaries and to practice basic skills. **Incidentally constructive action** Unplanned, unintentional, constructive action, that results by chance in an immediate, recognisable end product.

6

Recap of levels

Level of creative ability	Summary
3) Self-presentation	Presentation of self to others and developing the most basic and fundamental skills in social interaction. Exploring their abilities (body's, to control the environment, be constructive).
4) Passive participation	Motivation is directed towards establishing the rules and acceptable norms. Goal directed. Unable to initiate tasks independently. Can sustain interest in an activity that is structured and initiated by others. More refined emotions.

7

Recap of levels

Level of creative ability	Summary
5) Imitative participation	Predominantly directed at complying with the norms set by society. Individuality is evident, although requires a group/someone else who they are able to imitate. Motivation is product centred, with little evidence of initiative. Reluctance to compete and compare to others. Stressed by the unknown (where norm is unclear). Do what is asked on them – no more and no less.
6) Active participation	Motivation is directed at improving or changing aspects of activity/behaviour that they have identified as a problem. Improvement is based on their personal egocentric needs. Shows initiative, original thought and a developing ability to think broadly.

8

Definition of domains

Domain	Definition
Motivation	The inner force that directs all behaviour and results in the creation of products (tangible or intangible).
Action	"the exertion of motivation into mental and physical effort, which results in occupational behaviour and the creation of a tangible or intangible end product that is the outcome of doing".
Quality of product/Task concept	The outcome of action. Ability to comply with norms of product creation. Quality of performance and the ability to evaluate what they have done (including the standards they set for themselves).
Relational contact with the body	How they use their new body (hemiplegic) and level of norm awareness/compliance.

9

Definition of domains

Domain	Definition
Relational contact with tools and materials	Attitude to and ability to make relational contact with materials, objects, people and events in the environment. Awareness of tool handling norms.
Relational contact to the social world (people, situations)	To communicate and interact socially in familiar and unfamiliar situations, to make friends and develop lasting relationships and to read and comply with social norms in all situations.

10

Definition of domains

Domain	Definition
Control of anxiety	The ability to control anxiety when faced with routine tasks and new challenges. Appropriateness and broadness of emotional responses.
Ability to show initiative/make an effort	Important to note that this is different from exploration. Initiative is when self-confidence and intentionality are directed at finding new **successful** solutions to problems or new applications of known solutions. The ability to plan, initiate and sustain effort until the activity is done.

11

Definition of performance areas

Performance area	Definition
Personal management	The ability to: • Care for themselves and their personal business, according to the norms and culture of their society. • Acquire skills (toileting, dressing, washing etc.) and managing themselves independently within society.
Social ability	The ability to: • Interact and communicate socially with familiar and unfamiliar individuals. • Form acquaintances, make friends and develop lasting, stable, mature and intimate relationships.

12

Definition of performance areas

Performance area	Definition
Work ability	The ability to be productive and: • Initiate projects or tasks and see them through to conclusion, develop new ideas; • Manage themselves, their workload and resources effectively in the work and home environments, be it in open, sheltered, protective or an educational setting; • Work effectively according to norms; • Be critical of their performance through realistic judgement.
Use of leisure time	The ability to: • Use free time in a constructive, balanced, socially acceptable and recreational way in order to attain pleasure and de-stress.

13

Tone

- Motivation is directed at the will to live (biological systems).
- Defenceless, dependent and incapable.

14

Tone

Domain	Description
Motivation	**Egocentric to maintain existence**
Action	**Pre-destructive**

15

Tone

Domain	Description
Quality of product/Task concept	**None**
Relational contact with the body	

16

Tone

Domain	Description
Relational contact with tools and materials	**Not evident**
Relational contact with the social world	**No awareness**

17

Tone

Domain	Description
Control of anxiety	**Limited responses**
Ability to show initiative and make an effort	**None**

18

Tone

Performance area	Description
Personal management	
Social ability	

19

Tone

Performance area	Description
Work ability	
Constructive use of free time	

20

Self-differentiation

Establishing and maintaining self-awareness as a separate entity from the environment, objects and people in it.

Destructive action

- The most primitive interaction they have with the world. Destructive action aims to define their body boundaries and to practice basic skills.

Incidentally constructive action

- Unplanned, unintentional, constructive action, that results by chance in an immediate, recognisable end product.

21

Self-differentiation

Domain	Description
Motivation	**Egocentric - to differentiate self from others**
Action	**Destructive** **Incidentally constructive**

22

Self-differentiation

Domain	Description
Quality of product/Task concept	**None – basic elementary concepts**
Relational contact with the body	

23

Self-differentiation

Domain	Description
Relational contact with tools and materials	**Only simple everyday tools**
Relational contact with the social world	**Fleeting awareness**

24

Self-differentiation

Domain	Description
Control of anxiety	**Limited, uncontrolled. Comfort and discomfort are evident.**
Ability to show initiative and make an effort	**Fleeting, minimal**

25

Self-differentiation

Performance area	Description
Personal management	
Social ability	

26

Self-differentiation

Performance area	Description
Work ability	
Constructive use of free time	

27

Self-presentation

- Presentation of self to others and developing the most basic and fundamental skills in social interaction.
- Exploring their abilities (body's, to control the environment, be constructive).

28

Self-presentation

Domain	Description
Motivation	**To present self – unsure**
Action	**Explorative action (3-4 step task)**

29

Self-presentation

Domain	Description
Quality of product/Task concept	**Partial task concept, simple familiar activities with poor quality.**
Relational contact with the body	

30

Self-presentation

Domain	Description
Relational contact with tools and materials	**Basic tools for activity participation – poor handling**
Relational contact with the social world	**Tries to communicate superficially. Unsure and timid.**

31

Self-presentation

Domain	Description
Control of anxiety	**Varied, low self-esteem, anxiety; poor control.**
Ability to show initiative and make an effort	**Effort inconsistent, decreased frustration tolerance.**

32

Self-presentation

Performance area	Description
Personal management	
Social ability	

33

Self-presentation

Performance area	Description
Work ability	
Constructive use of free time	

34

Passive participation

- Motivation is directed towards establishing the rules and norms acceptable to the group and society.
- Goal directed.
- Unable to initiate tasks independently.
- Can sustain interest in an activity that is structured and initiated by others.
- More refined emotions.

35

Passive participation

Domain	Description
Motivation	**Robust. Directed to the attainment of skills.**
Action	**Product centred and task fulfilment (5-7 step task).**

36

Passive participation

Domain	Description
Quality of product/Task concept	**Total task concept, product of fair quality (aware of expectations).**
Relational contact with the body	

37

Passive participation

Domain	Description
Relational contact with tools and materials	**Appropriate skills.**
Relational contact with the social world	**Communicates. Acts as a follower (passive) in a variety of situations.**

38

Passive participation

Domain	Description
Control of anxiety	**Full range of emotions, mostly controlled.**
Ability to show initiative and make an effort	

39

Passive participation

Performance area	Description
Personal management	
Social ability	

40

Passive participation

Performance area	Description
Work ability	
Constructive use of free time	

41

Imitative participation

- Predominantly directed at complying with the norms set by society.
- Individuality is evident, although requires a group/someone else who they are able to imitate.
- Motivation is product centred, with little evidence of initiative. Reluctance to compete and compare to others.
- Stressed by the unknown (where norm is unclear).
- Do what is asked on them – no more and no less.

42

Imitative participation

Domain	Description
Motivation	**Directed to product, acceptable behaviour.**
Action	**Imitative in nature. Product centred (7-10 step tasks)**

43

Imitative participation

Domain	Description
Quality of product/Task concept	**Comprehensive task concept. Product of good quality, according to expectations.**
Relational contact with the body	

44

Imitative participation

Domain	Description
Relational contact with tools and materials	**Good**
Relational contact with the social world	**Interacts, manages a variety of situations appropriately.**

45

Imitative participation

Domain	Description
Control of anxiety	**Compassion and self-awareness, anxiety-used.**
Ability to show initiative and make an effort	

46

Imitative participation

Performance area	Description
Personal management	
Social ability	

47

Imitative participation

Performance area	Description
Work ability	
Constructive use of free time	

48

Active participation

- Motivation is directed at improving or changing aspects of activity/behaviour that they have identified as a problem. Improvement is based on his personal egocentric needs.
- Shows initiative, original thought and a developing ability to think broadly.

49

Active participation

Domain	Description
Motivation	**Directed to the improvement of product, procedures.**
Action	**With originality – transcends norm expectations.**

50

Active participation

Domain	Description
Quality of product/Task concept	**Abstract reasoning. Can adapt, modify, exceed, evaluate and upgrade.**
Relational contact with the body	

51

Active participation

Domain	Description
Relational contact with tools and materials	**With initiative**
Relational contact with the social world	**Close interpersonal relationships, can assist others, consideration. Can deal with problems.**

52

Active participation

Domain	Description
Control of anxiety	**Anxious in new situations, normal emotional responses.**
Ability to show initiative and make an effort	**Consistent, original.**

53

Active participation

Performance area	Description
Personal management	
Social ability	

54

Active participation

Performance area	Description
Work ability	
Constructive use of free time	

55

Outline for the outcome measure

Domain	Tone	Self-differentiation	Self-presentation	Participation		
				Passive	Imitative	Active
[illegible]						
[illegible]						
[illegible]						
[illegible]						
[illegible]						
[illegible]						
[illegible]						
[illegible]						

56

Outline for the outcome measure

Domain	Tone	Self-differentiation	Self-presentation	Participation		
				Passive	Imitative	Active
Personal management						
Social ability						
Work ability						
Constructive use of free time						

57

References

- du Toit V. Patient volition and action in occupational therapy. Pretoria, South Africa: The Vona & Marie du Toit Foundation; 2009.
- Crouch R, Alers V. Occupational therapy in psychiatry and mental health, 4th ed. London, England: Whurr Publishers London and Philadelphia; 2005.

58

Annexure F

Framework for the outcome measure

Framework for the outcome measure

Domain	Tone	Self-Differentiation	Self-Presentation	Participation		
				Passive	Imitative	Active
Action						
Motivation						
Quality of product or performance and task concept						
Relational contact with the body						
Relational contact with materials and tools						
Relational contact to the social world						
Control of anxiety						
Ability to show initiative and make an effort						

Performance area	Tone	Self-Differentiation	Self-Presentation	Participation		
				Passive	Imitative	Active
Personal management						
Social ability						
Work ability						
Constructive use of free time						

Annexure G

Letter of approval from Ethics Committee at the University of Pretoria

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

1/02/2018

Approval Certificate
New Application

Ethics Reference No: 37/2018

Title: DEVELOPMENT OF AN OUTCOME MEASURE BASED ON MOTIVATION AND ACTION FOR OCCUPATIONAL THERAPISTS IN NEUROLOGICAL REHABILITATION

Dear Ms Samantha Lee

The **New Application** as supported by documents specified in your cover letter dated 23/01/2018 for your research received on the 24/01/2018, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 31/01/2018.

Please note the following about your ethics approval:
- Ethics Approval is valid for 2 years
- Please remember to use your protocol number (**37/2018**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:
- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

*** Kindly collect your original signed approval certificate from our offices, Faculty of Health Sciences, Research Ethics Committee, Tswelopele Building, Level 4-60*

Dr R Sommers; MBChB; MMed (Int); MPharMed,PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

☎ 012 356 3084 deepeka.behari@up.ac.za / fhsethics@up.ac.za http://www.up.ac.za/healthethics
✉ Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 60 / 61, 31 Bophelo Road, Gezina, Pretoria

Annexure H

The Motivation and Action in Neurological Rehabilitation Outcome Measure (MANROM)

Motivation and Action in Neurological Rehabilitation Outcome

Patient's name: _____
Date: _____
Therapist: _____

Domains	Tone	Self-Differentiation	Self-Presentation	Participation		
				Passive	Imitative	Active
Motivation	**Motivationally blank** • Unresponsive • Dependent on others and machines for survival **Physiological maintenance** **Glascow Coma Scale score of 0-5** **Maslow's Hierarchy of Needs Stage 1 –** biological and physiological needs	**Egocentric** • Based on an immediate need • Instant gratification **To differentiate self from the environment in order to establish body boundaries** • Pulling out tubes • Protecting self from noxious stimuli **Glascow Coma Scale score of 6-9** **Maslow's Hierarchy of Needs Stage 2** – safety needs	**To present self** • Attempts to participate • Motivation is developing towards constructive action **Unsure, externally motivated** • Requires constant supervision and positive feedback **Glascow Coma Scale score of 10-12** **Maslow's Hierarchy of Needs Stage 2 or 3** – safety, love and belongingness needs	**Directed to the attainment of skills and establishing rules and norms** • To meet physical, social and task norms **Externally motivated** • To meet norms and please others **Glascow Coma Scale score of 13-15** **Maslow's Hierarchy of Needs Stage 3** – love and belongingness needs	**Intrinsically motivated to achieve something** • Money • Belonging • Normal movement • What they lost **Glascow Coma Scale score of 15** **Maslow's Hierarchy of Needs Stage 4** – esteem needs	**Directed to the improvement of self** • Physical, vocational, cognitive, social **Glascow Coma Scale score of 15** **Maslow's Hierarchy of Needs Stage 5** – self-actualisation needs
Action	**Pre-destructive** • No action • Purposeless, unintentional **Reflexive and involuntary** **Rancho Los Amigos Level 1 or 2**	**Destructive** • Restrained • Pulling out tubes • Aggressive • Restless • Destructive action to their own health **Incidentally constructive** • 1 step • Automatic and unintentional • Splint skills (eating) **Emergence of participation** • Attempts to engage • No plan **Rancho Los Amigos Level 3 or 4**	**Explorative** • Unplanned • Exploring body • Fearful and unsafe • Testing the limits of their new body (standing up without the necessary strength) **Facilitated** • Requires prompting and set-up **1-2 steps** with global instructions **3-4 steps** with step by step instructions **Rancho Los Amigos Level 5 or 6**	**Skills or product centred** • Action is focused on attaining skill • Able to complete basic tasks independently with set-up **Therapist directed** • Passive • Requires prompting, cues and supervision **Safe** **2-4 steps** with global instructions **5-7 steps** with step by step instructions **Rancho Los Amigos Scale Level 7**	**Imitative** • Imitate norms and premorbid function **Norm directed** • Imitate normal function and normal movement **7-10 steps** • Good task concept in familiar and unfamiliar tasks within an established routine **Rancho Los Amigos Scale Level 8**	**With originality, transcends the norms** • Action is aimed at improving own skills and meeting or exceeding the norms **Rancho Los Amigos Scale Level 9 or 10**

Domains	Tone	Self-Differentiation	Self-presentation	Participation		
				Passive	Imitative	Active
Quality of product or performance and task concept	**None**	**Emergence of participation in basic, physiological need tasks** • Survival • Eating • Participation in response to a need (hunger, thirst or cold) • 1 step • Automatic, in a familiar task • Not a conscious effort **Poor quality of product or performance** • Unaware of the norms • Large gross motor movements	**Partial task concept** • Familiar activities • Prompting and set-up in all phases of task concept • Poor task completion **Poor quality of product or performance** • Messy • Unable to evaluate • Developing awareness of the norms but unable to comply	**Consolidated task concept for basic tasks** • Good understanding of BADL's **Requires facilitation for initiation. Can continue with execution and completion** • Unable to problem solve to improve performance **Aware of the norms but not compliant** • Product of fair quality (establishing norms, but compliant) • More interested in task participation than completion **Concrete evaluation**	**Full task concept** • Independent in ADL's with an established routine • Unable to set up own routine • Able to imitate a programme • Participates in less familiar or basic tasks within a routine (such as washing the dishes) **Product or performance of good quality** • Normal movement • Safe **Able to evaluate end product according to norm** • Look for norms as a comparison	**Full task concept** • Abstract reasoning • Can adapt, modify, exceed, evaluate and upgrade **Product or performance of good quality.** • Able to evaluate end product • Meets and exceeds the norms
Relational contact with the body	**No body awareness** • Involuntary response to noxious stimuli **Neglect of the affected side** • Visual and physical neglect noted by positioning in bed **Reflexive** • Posturing in response to stimulation	**Emerging body concept** • Aware of the unaffected • Uses unaffected side in tasks **Neglect of the affected side** • Emerging awareness that something is different • Unable to use affected side in tasks	**Increased awareness of abilities with improved body concept** • Uses unaffected side as needed • Compensates **Learned non-use develops** • Facilitation required for full body awareness • Would rather compensate to complete task	**Aware of affected limb and theory regarding care** • Unable to initiate fixing the limbs positioning **Compensatory strategies used** • Focused on completing the task according to the norms **If facilitated - purposeful, safe use of the body**	**Acceptance of new body image, still working for recovery** • Realistic perception of the body • Aware of limitations and abilities and able to compensate **Able to care for hemiplegic side independently** • Correcting the limbs position • Performing stretches • Providing proprioceptive inputs	**Acceptance of new body image, still working for recovery** • Takes initiative for own recovery - will research new techniques • Working to full return of function **Too motivated or pre-occupied with improving**

Domain	Tone	Self-Differentiation	Self-Presentation	Participation		
				Passive	Imitative	Active
Relational contact with tools and materials	**None**	**Basic, familiar tools** • Uses daily, familiar tools (spoon) • Automatic (eating) **Inappropriate use** • Mouths everything **Requires maximum facilitation to engage with tools** • Requires set-up	**Basic** • Identifies familiar tools • Explores with the unaffected side **Aware but not compliant with the norms of tool handling** • Poor quality of tool use (using the wrong side of the hairbrush)	**Aware of the purpose of tools** • Uses tools for their intended purpose **Able to use assistive devices with guidance**	**Appropriate use of tools including assistive devices** **Tools and materials used for their intended purpose** • Little abstract thinking to change the purpose of a tool to suit their needs	**Able to use familiar tools and assistive devices** • Appropriately • With initiative **Able to adapt equipment according to their needs**
Relational contact with the social world	**Reflexive** • Startle response **Fleeting awareness of familiar voices and faces** • Responds momentarily by looking towards stimulus • Unable to sustain eye contact	**Fleeting or brief contact with familiar people** • Fleeting awareness of others • Brief eye contact on the unaffected side • Turns towards familiar people • Unable to initiate interaction **Unaware of social norms** • Emotional with familiar people • Inappropriate indication of discomfort (screaming, crying or aggression)	**Egocentric** • Based on needs and wants **Automatic speech** • Pleasantries • Not always reciprocal **Emerging intent to interact** • Aware of others • Unable to initiate interaction • Interacts with therapists	**Superficial, concrete, current** • Unable to reciprocate • Related to their current situation **Interacts with facilitation by others** • Acts as a follower • Able to have a basic conversation **Aware of the social norms but not compliant** **Passive participant in a support group**	**Norm compliant, aware of social cues** • Socially acceptable **Able to handle a variety of situations** • Imitates norm compliant individuals in unfamiliar situations **Rely on others to initiate interaction** • Will interact with friends and family within a routine • Unable to sustain friendships independently **Involved in support groups**	**Interacts appropriately with familiar and unfamiliar people** • Able to initiate and sustain contact • Can assist others • Have close interpersonal relationships **Handles unpredictable situations independently** **Involved in support groups** • May initiate or lead the group

Domains	Tone	Self-Differentiation	Self-Presentation	Participation		
				Passive	Imitative	Active
Control of anxiety	**No anxiety** • Unaware	**Emotionally labile** • Exaggerated emotions **Comfort and discomfort are evident** **Low frustration tolerance** • Easily give up or shut off	**Emotionally labile, poor emotional control** **Fearful, low self-esteem** • Increased insight into fallouts • Requires success	**Names and recognises concrete emotions** **Depression -** due to increased awareness of social norms and non-compliance as well as physical limitations	**Expresses, controls and displays a variety of emotions** • Appropriate • Compassion • Able to apply coping mechanisms in familiar situations • Can start emotional therapy **Anxious in unfamiliar situations** • Unable to problem solve in unfamiliar situations	**Normal range of emotions** **Controls emotions independently in all situations** • Anxiety does not overwhelm function • Applies coping mechanisms
Ability to show initiative and make an effort	**None**	**Unable to initiate** • Unable to problem solve • Dependent for home exercise programme **Effort is in response to a physiological need** • Engages in BADL's • In response to a need (food)	**Poor initiative** • Makes an effort • Unplanned • Dependent on others to follow home exercise programme **Poor frustration tolerance, unable to sustain effort** • Low perseverance • Refuses therapy	**Able to initiate and make a sustained effort to fulfil a need, with set-up** • BADL's • Effort is sustained, • Unable to follow exercise programme independently • Improved execution in a routine **Unable to problem solve within a task**	**Able to initiate and put maximum effort into meaningful tasks** • Effort is sustained until task completion • Follows home exercise programme independently • No extra effort is given **Able to problem solve concrete problems** (how to fix a label that ensure that it is straight) **Unable to problem solve in unknown situations**	**Shows initiative in all situations** • Self-driven • Identifies and solves problems • Follows and improves on home exercise programme **Sustains maximum effort to reach long term goals** • Persistent • Puts effort into others

Performance areas	Tone	Self-Differentiation	Self-Presentation	Participation		
				Passive	Imitative	Active
Personal management	**Totally dependent**	**Dependent** • Unable to initiate • Poor awareness of the need to perform self-care tasks **Able to participate with maximum facilitation** • 1 step	**Dependent, aware of norms** • Actively involved in BADL's with prompting and set-up • Poor quality (only fix one side of their hair or stop participating in the task before completion) **Responds better to a routine that is managed for them**	**Participates independently in BADL's within a routine, with set-up** • Poor quality - aware of norms, not compliant **Starting simple IADL's with prompting and set-up** • Better with a routine	**Independent** • Showing personal style **Starting with IADL's** • Within a routine • Cleaning, cooking, washing dishes	**Independent** • Good quality • Personal style evident **Independent in IADL's** • Personal affairs
Social ability	**None**	**Egocentric** • Not reciprocal • Based on own needs **Able to recognise familiar people** • Turn towards familiar people	**One on one level** • Functions in parallel to others within a group **Dependent on others** • No intent to initiate interaction • Can interact with facilitation **Poor compliance with social norms** • Unable to differentiate behaviour between known and unknown	**Able to interact with set-up** • Starts to make friends in the ward • Able to follow basic conversation **Can be included in groups** • Participates passively • Task-orientated	**Reciprocal** • Shows interest in others • Able to interact with familiar and unfamiliar • Active participant in the community **Want to interact** • Want to be part of a community • Others must initiate the interaction or include it in a routine	**Appropriate with familiar and unfamiliar people** • Able to differentiate between social norms with familiar and unfamiliar people **Forms relationships independently**

Performance area	Tone	Self-Differentiation	Self-Presentation	Participation		
				Passive	Imitative	Active
Work ability	**None**	**None**	**Sheltered** • Repetitive • Constant supervision • Demonstration • Low production (less than 50%)	**Sheltered** • Routine • Repetitive • Will follow job description • Supervision required	**Open labour market** • Reasonable accommodations • Work dependent • Predictable • Able to meet job description – no extra effort • Few social demands **Able to study** • Short courses	**Open labour market** • supervisory or managerial positions • Suggests own reasonable accommodations • Occupation dependent • Works towards a promotion or improving self **Able to study** • Long term (degrees, diplomas)
Constructive use of free time	**None**	**None**	**Passive** • Facilitated by others • Sleep	**Passive** • Requires prompting to participate in tasks • Will sit passively with task next to them • TV, radio	**Will participate in meaningful tasks** • Independent within a routine • Not competitive • Return to previous leisure tasks (dependent on their physical abilities)	**Constructive** • Initiates projects • Creative • Explores new tasks • Aware of the benefit of leisure • Adapts tasks to suit physical abilities
TOTAL						
LEVEL						