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Seward, Caroline Claire

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PSYCHOMETRIC PROPERTIES OF THE SELF-CARE INVENTORY FOR CHILDREN WITH CEREBRAL PALSY IN A RESOURCE-CONSTRAINED URBAN SOUTH AFRICAN CONTEXT

Caroline Claire Seward

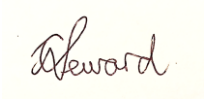
A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.

Johannesburg

June 2020

Declaration

I, **Caroline Claire Seward**, hereby declare that this research report is my own work. It is being submitted for the degree of Masters of Science in Occupational Therapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Signature 

12th Day of **June**, 2020.

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

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

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Dedication

I dedicate my research report to the caregivers of the children with cerebral palsy with whom I have worked and Patricia (Tumi) Matlou and her daughter, Kgomotso. Their commitment to the well-being of their children is inspirational.

Acknowledgments

I would like to thank my research supervisor, Dr Denise Franzsen, for her continuous support and guidance throughout this research process. You have been a tremendous help and enhanced the quality of this research with your expert opinion. Thank you to my research assistant, Patricia (Tumi) Matlou. I would not have been able to complete my data collection without you. Thank you for your support, passion and dedication in assisting families with children with cerebral palsy. Thank you also to Julia Burg, who completed her dissertation with the creation of the Self-Care Inventory for Children with Cerebral Palsy (SCICP) in 2016. I hope that I have assisted in validating this tool so that in the future it may be used in widespread clinical practice in South Africa.

Abstract

There is a lack of contextually appropriate and standardised assessment tools in South Africa. The Self-Care Inventory for Children with Cerebral Palsy (SCICP) was initially developed in Gauteng as a caregiver report questionnaire to assess the self-care abilities of children with cerebral palsy (CP) living in poorly resourced and low socio-economic areas in KwaZulu- Natal, South Africa. The tool underwent initial field testing and content validity so as to determine administration and item appropriateness. Burg (2016) recommended that the tool undergo further validity and reliability testing so as to enhance its psychometric properties. Eventually, it is hoped that the tool may be used as a standardised assessment within the South African context.

A cross-sectional, non-experimental study design was used that was quantitative in nature. Two hospitals in the Ekurhuleni district in Gauteng, South Africa were used as the sites of data collection. Fifty CP children and fifty typical children's caregivers were asked to complete a demographic questionnaire as well as the study's assessment tool, the SCICP. Data obtained from these two sources were converted into numerical data for analysis by descriptive statistics. This data is depicted in the form of tables and graphs. The objectives of this study were as follows: to determine the known-group validity of the SCICP for children between the ages of nought to six-years-old who are typically developing and compare it to children with CP between the ages of nought-to eight-years-old. And to determine the content validity (response process and relationship to other measures) of the SCICP for the two sample groups of children. Additional objectives were to determine the internal consistency, as well as the sensitivity, specificity and accuracy of the tool.

The SCICP has been shown to differentiate between children who are typically developing and children with CP who present with developmental delay. The known-group validity between the two groups showed significant differences for the test score of typically developing children and the children with CP across all self-care domains for the majority of the different age groups. Further response process was confirmed by the strong correlation of the test scores of the children with CP and their GMFCS levels. Lower correlations were found with the children's MACS levels. Age was not significantly correlated with the SCICP test scores for children with CP.

A moderate correlation was found between the caregivers' report scores and therapist's scores after observing selected tasks on the SCICP. The SCICP showed acceptable internal consistency of over 0,70. Overall sensitivity of 87,5% and specificity of 74,4%. Accuracy scores were 80,9% overall and ranged from 69-100% for the different age groups in identifying children with developmental delay in self-care. Multiple factors are responsible for children with CP's ability to perform their self-care skills, most notably their gross motor skills and hand functioning. The SCICP shows promising results for use in the clinical setting from the psychometric properties that were tested.

Table of Contents

Declaration i
Dedication iii
Acknowledgments iv
Abstract v
Table of Contents vii
List of Tables xii
List of Figures xiii
Operational Definitions xiv
Abbreviations xvii
CHAPTER 1: INTRODUCTION 1
1.1 Introduction and background to the study 1
1.2 Statement of the problem 3
1.3 Purpose of research study 3
1.4 Research question 3
1.5 Research aim 3
1.6 Research objectives 4
1.7 Significance of the study 4
1.8 Organisation of the research report 4
CHAPTER 2: LITERATURE REVIEW 7
2.1 Introduction 7
2.2 The importance of occupation in occupational therapy 7
2.2.1 Occupational participation in children with cerebral palsy 8
2.2.2 The importance of assessment in occupational therapy and in children with cerebral palsy 9
2.3 Contextually relevant assessments tools 11
2.3.1 Assessment tools for children with cerebral palsy 12
2.3.1.1 Standardised assessments for classification systems for children with cerebral palsy 12
2.3.1.2 Standardised assessments for self-care for children with cerebral palsy .. 14
2.3.1.3 Assessment tool for activities of daily living for children with cerebral palsy developed in South Africa 21
2.4 Properties of screening assessment tools 24
2.5 Defining assessment tool reliability and validity 27
2.6 Summary 29

CHAPTER 3: METHODOLOGY 31
3.1 Introduction to methodology 31
3.2 Research design 31
3.3 Site of research 32
3.4 Population and sample 34
3.4.1 Inclusion criteria 35
3.4.2 Sample size 35
3.5 Measurement instruments 36
3.5.1 Demographic questionnaire 36
3.5.2 Self-Care Inventory for Children with Cerebral Palsy 36
3.5.2.1 Caregiver report or interview with caregiver 36
3.6 Research procedure 37
3.6.1 Translation of the Self-Care Inventory for Children with Cerebral Palsy 37
3.6.2 Training the research assistants 37
3.6.3 Pilot study 38
3.6.4 Stratification of the sample 39
3.7 Data collection 39
3.7.1 Caregivers of typically developing children 39
3.7.2 Caregivers of children with cerebral palsy 40
3.7.3 Observation of typically developing children and children with cerebral palsy 41
3.8 Data analysis 42
3.9 Ethical considerations 43
3.9.1 Accountability and honesty in the conduct of research 44
3.9.2 Professional courtesy and fairness in working with others 44
3.9.3. Good stewardship of research on behalf of others 44
3.10 Summary 45
CHAPTER 4: RESULTS 46
4.1 Introduction 46
4.2 Demographic information 46
4.2.1 Personal demographics of the children 46
4.2.2 Birth history of children with cerebral palsy and typical children 48
4.2.2.1 Birth mode 48
4.2.2.2 Gestational period of children with cerebral palsy and typical children in weeks 48
4.2.2.3 Birth complications 49
4.2.3 Medical history – children with cerebral palsy 51

4.2.3.1 Types of cerebral palsy 51
4.2.3.2 Classification scale levels for children with cerebral palsy 52
4.2.3.3 Hearing and visual impairment 52
4.2.3.4 Feeding impairment 53
4.2.3.5 Epilepsy 53
4.2.4 Socio-economic indicators 54
4.2.4.1 Caregiver and household employment 54
4.2.4.2 Social grants 55
4.2.4.3 Household amenities 56
4.3 Self-Care Inventory for Children with Cerebral Palsy 57
4.3.1 Objective 1: To determine the known-group validity of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay. 57
4.3.1.1 Typical children 57
4.3.1.2 Children with cerebral palsy 59
4.3.2 Between group scores 61
4.3.2.1 Differences between the typical children and children with cerebral palsy scores according to age 62
4.3.3 Objective 2: To determine the content validity (response process and relationship to other measures) of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay. 64
4.3.3.1 Correlation of Self-Care Inventory for Children with Cerebral Palsy and observations of self-care tasks 64
4.3.3.2 Relationship between the Self-Care Inventory for Children with Cerebral Palsy and age group, Gross Motor Function Classification System (GMFCS) level and Manual Abilities Classification System (MACS) level 64
4.3.4 Objective 3: To determine the diagnostic accuracy in terms of sensitivity, specificity of the SCICP for children with CP and typically developing children aged one to six years 66
4.3.5 Objective 4: To determine the internal consistency of the SCICP for children with CP aged one to eight years 68
4.4 Summary 69
CHAPTER 5: DISCUSSION 71
5.1 Introduction 71
5.2 Demographic and medical information 71

5.2.1 Demographics 71
5.2.2 Medical history of children 73
5.3 The Self-Care Inventory for Children with Cerebral Palsy information 75
5.3.1 Objective 1: To determine the known-group validity of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay. 75
5.3.2 Objective 2: To determine the content validity (response process and relationship to other measures) of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay. 77
5.3.2.1 Response process- Observation of the child 77
5.3.2.2 Relationship between variables -Level of function, age and self-care 80
5.3.3 Objective 3: To determine the diagnostic accuracy in terms of sensitivity, specificity of the SCICP for children with CP and typically developing children aged one to six years 82
5.3.4 Objective 4: To determine the internal consistency of the SCICP for children with CP aged one to eight years 83
5.4 Strengths and limitations of the study 84
5.4.1 Strengths of the study 84
5.4.2 Limitations of the study 85
5.5 Clinical implications 87
5.6 Summary 89
CHAPTER 6: CONCLUSION 91
6.1 Main findings of the study 91
6.2 Recommendations 93
REFERENCES 96
APPENDIX A DEMOGRAPHIC QUESTIONNAIRE 106
APPENDIX B SELF-CARE INVENTORY FOR CHILDREN WITH CEREBRAL PALSY (SCICP) 108
APPENDIX C ETHICAL CLEARANCE 124
..... 124
APPENDIX D PERMISSION FROM THE CEO, THE HEAD OF PAEDIATRICS AND THE HEAD OF THE OCCUPATIONAL THERAPY DEPARTMENT AT TAMBO MEMORIAL HOSPITAL 125
APPENDIX E PERMISSION TO CONDUCT RESEARCH AT THELLE MOGOERANE REGIONAL HOSPITAL 134

APPENDIX F PARTICIPANT INFORMATION SHEET 135
APPENDIX G INFORMED CONSENT FORM 137
APPENDIX H WRITTEN CAREGIVER INFORMED CONSENT FORM FOR PHOTOGRAPHS/VIDEO 138
APPENDIX I VERBAL ASSENT FOR CHILDREN 139
APPENDIX J TURNITIN REPORT 140
APPENDIX K PHOTOGRAPHS FROM OBSERVATION 141
Typical child 141
Children with cerebral palsy 141

List of Tables

Table 2.1: Brief overview of existing assessment tools for the paediatric population 16
Table 3.1: Data Analysis 43
Table 4.1: Ages of children with cerebral palsy and typical children 47
Table 4.2: Birth mode of children with cerebral palsy and typical children 48
Table 4.3: Gestational period of children with cerebral palsy and typical children in weeks 49
Table 4.4: Birth complications of children with cerebral palsy and typical children 50
Table 4.5: Gross Motor Function Classification System (GMFCS) level and Manual Abilities Classification System (MACS) level for children with cerebral palsy 52
Table 4.6: Hearing and visual impairment children with cerebral palsy 53
Table 4.7: Levels of employment of caregivers of children with cerebral palsy and typical children 54
Table 4.8: Access to water and electricity in households for children with cerebral palsy and typical children 56
Table 4.9: Typical children within group scores 58
Table 4.10: Children with cerebral palsy within group scores 60
Table 4.11: Confidence interval range for overall point scores 62
Table 4.12: Significant differences in test scores by age 63
Table 4.13: Age, Gross Motor Function Classification System (GMFCS) level and Manual Abilities Classification System (MACS) level correlations for children with cerebral palsy 65
Table 4.14: Sensitivity and specificity of the Self-Care Inventory for Children with Cerebral Palsy 67
Table 4.15: Internal consistency using Cronbach's alpha for children with cerebral palsy and typical children total groups 69

List of Figures

Figure 4.1: Gender distribution of children with cerebral palsy and typical children 47
Figure 4.2: Types of cerebral palsy 51
Figure 4.3: Employment rates per household for children with cerebral palsy and typical children 55
Figure 4.4: Social grants received for children with cerebral palsy and typical children 56
Figure 4.5: Overall median point scores comparing children with cerebral palsy and typical children ages one to six-years-old 61

Operational Definitions

Cerebral palsy

CP is the term used to describe a group of permanent neurologic disorders, which predominantly affects movement and posture. This group of disorders is as a result of a non-progressive insult to the foetal, or developing, brain. The nature of cerebral palsy is heterogeneous and is associated with a number of co-morbid conditions such as epilepsy, intellectual disability, sensory disorders and behavioural problems (Donald *et al.*, 2015).

Content validity

Experts support that the tool has the suitable content. *Response process* involves information about whether the actions or thoughts of the participants actually match the test. *Relationship to other variables* comprises correlation of the new assessment instrument results with other performance outcomes (Sullivan, 2011).

Context and environment

Participation in occupations takes place within an environment, which is situated within a particular context. According to the OTPFIII, the numerous and interrelated variables within a person's environment and context influence the way in which they participate and engage in occupations. Both the physical and the social environment need to be taken into consideration as well as the cultural, personal, virtual and temporal contexts when considering how self-care tasks are carried out (American Occupational Therapy Association, 2014).

Diagnostic accuracy

The accuracy of diagnostic tests provides reliable information about a client's illness status and, thus, influence client care. When developing assessment tools, the discerning power is based on the sensitivity and specificity of the test (Mandrekar, 2010),

Evaluation

"Evaluation is the process of obtaining and interpreting data necessary for intervention. This includes planning for, and documenting, the evaluation process and results" (American Occupational Therapy Association, 2008: 107).

Functional mobility

Mobility is vital to a person's overall functioning and development in occupations. Functional mobility refers to

	an individual's ability to move from one position to another (Case-Smith and O'Brien, 2010).
Internal consistency	Internal consistency explains the relationship between test items and the degree to which items on the test measure the same thing. Internal consistency can be estimated after one administration of the test (Bolarinwa, 2015). If the relationship between test items is strong, this strengthens the internal consistency, or homogeneity, of the assessment tool.
Known-group validity	Known-group validity is a measure of a group's established characteristics against another group in which those characteristics are not known. It is expected that the construct identifying the condition in the questionnaire will have a significantly different score for clients with the condition when compared to those without the condition (Bolarinwa, 2015).
Low socio-economic status	Low socio-economic status is a measure of a combination of economic and sociological indicators. Indicators are based on things such as; level of education, household amenities and housing conditions, income and occupation based measures. with less access to proper housing conditions and basic amenities such as water and electricity, whether a toilet is inside or outside of the home and if the person or family has access to appliances, constitutes various types of household amenities. The type of occupation and employment of a person also contributes significantly to socio-economic status (Galobardes *et al.*, 2006).
.	
Participation	Participation occurs when clients are involved actively in performing occupations that they find meaningful. Participation requires the choice of the activity, motivation to perform the activity and support from the context and environment in order to engage in the occupation (American Occupational Therapy Association, 2014).

Resource-constrained context	A resource-constrained context refers to an environment that lacks economic, social and technical resources. Examples of these resources could be infrastructure, purchasing power, financial activities and access to education. In a discussion paper published by UNICEF, Fajth and Holland (2007) stated various factors that could consider a context resource-constrained. They are the following; a lack of adequate shelter with many persons staying in one shelter, lack of access to sanitation facilities, poor access to safe drinking water, lack of information, which constitutes a lack of access to radio, television, newspapers or computers, a lack of food and a lack of educational and health facilities.
Self-care	Activities that focus on a person's ability to look after themselves and is essential to living in any environment. Self-care can also be referred to as participation in activities of daily living (ADLs) that are needed for survival (Christiansen and Hammecker, 2008). These activities include, bathing and showering, dressing, toileting and toilet hygiene, swallowing/eating, feeding, functional mobility, personal device care, personal hygiene and grooming (American Occupational Therapy Association, 2014).This list is not exhaustive. For the purposes of this study the term self-care will be used to describe participation in these occupations.

Abbreviations

ADLs	Activities of daily living
AOTA	American Occupational Therapy Association
BADLs	Basic activities of daily living
CEO	Chief executive officer
CP	Cerebral palsy
CFCS	Communication Function Classification System
CVI	Cerebral visual impairment
EDACS	Eating and Drinking Ability Classification System
FM	Functional mobility
GAS	Goal Attainment Scaling
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning, Disability and Health
LMIC	Low and middle-income countries
MACS	Manual Ability Classification System
MO	Malamulele Onward
NNE	Neonatal encephalopathy
NNJ	Neonatal jaundice
NSS	Normative standard scores
NVD	Normal vaginal delivery
OT	Occupational Therapist
OTPF III	The Occupational Therapy Practice Framework 3rd edition
PADLs	Personal activities of daily living
PEG	Percutaneous endoscopic gastrostomy
SASSA	South African Social Security Agency

SCICP	Self-Care Inventory for Children with Cerebral Palsy
SME	Subject Matter Expert
TMH	Tambo Memorial Hospital
TMRH	Thelle Mogoerane Regional Hospital

CHAPTER 1: INTRODUCTION

1.1 Introduction and background to the study

The occupational therapy process is comprised of several steps; the first step being the evaluation process, which includes the gathering of information and the interpretation of data needed to plan intervention (American Occupational Therapy Association, 2008). Accurate assessment, or evaluation, is crucial in order to determine outcomes for therapy and provide guidelines for intervention. Successful participation in activities is the end result of occupational therapy intervention (American Occupational Therapy Association, 2014).

Early intervention comprises any services provided to caregivers and their children from the time of conception until the start of formal schooling. Research has found that early childhood intervention improves a child's holistic development and educational outcomes. Longitudinal studies in the United Kingdom and the United States of America describe positive results for the impact of early intervention in all developmental domains of language, cognition, socio-emotional, interpersonal and motor functioning (Matafwali and Serpell, 2014). Studies conducted in Sub-Saharan Africa have also noted improved academic outcomes for children enrolling in Grade 1. Matafwali and Serpell (2014) describe a number of benefits that can be obtained by assessment of young children. Accurate assessment can aid identification of children who may be at risk for disability and who may have special educational needs. Through appropriate assessment, intervention planning can be more specific and the accurate monitoring of children's developmental progress may be conducted. Literature has shown that this will lead to an improvement in the overall participation of children in their daily tasks and decrease the burden of care on caregivers (Mathye and Eksteen, 2016; Klutse and Naab, 2018; Abdel Malek, Rosenbaum and Gorter, 2020).

The prevalence of CP in developed countries is between approximately 2-2.5 per 1000 live births (Oskoui, 2013). In developing countries in Africa, even though there are concerns of an underreporting of CP, the prevalence is still considered to be greater. In a study conducted by Couper (2002), the prevalence of CP in a rural community in KwaZulu-Natal was as many as 10 per 1000 live births. In South

Africa, children surviving intrapartum-related causes of CP, such as intrapartum hypoxia, are considered to be significantly higher than that of developed countries (Cooper, 2015). A retrospective study conducted at Chris Hani Baragwanath Academic Hospital revealed neuroimaging reports suggestive of hypoxic ischemic injury in 42% of the total 144 cases reviewed (Pattinson and Rhoda, 2012).

Children with CP often fall short of the typical developmental trajectory and, thus, experience barriers to participation in ADLs. Children's participation in an ADL such as self-care, has been found to be of great importance to caregivers (James, Ziviani and Boyd, 2014). However, due to limitations in gross motor ability, hand function, cognition and other associated impairments, children with CP are not able to complete these activities independently (Gunel *et al.*, 2009). In order to accurately assess the extent to which children with CP experience restrictions in their participation, appropriate standardised assessment tools are needed to initiate the occupational therapy process.

Many authors have cited that there is a lack of standardised assessment tools for non-Western paediatric populations (Gladstone *et al.*, 2010; Matafwali and Serpell, 2014; Burg, 2016). Burg (2016) highlighted in her research study that within current occupational therapy practice in South Africa, there are no contextually relevant assessment tools to assess the self-care tasks of children with CP. Due to the lack of standardised assessment tools for developing countries and the high prevalence of children with CP in Africa, Burg (2016) developed the SCICP in 2016. This assessment tool has been developed for African children from a low socio-economic context living in South Africa. It is a caregiver report questionnaire and focuses specifically on a child's level of independence in performing their self-care tasks. Self-care forms the foundation for participation in all ADL tasks. Children's successful participation in their self-care tasks is viewed with great importance by caregivers (James, Ziviani and Boyd, 2014).

Although Burg's study underwent a number of processes in order to develop the SCICP, further research is needed in order to establish the psychometric properties of the assessment tool. This study aimed to address aspects of reliability and validity, namely, known-group validity of the tool as well as establish the content

validity (response process and relationship to other measures), internal consistency and sensitivity, specificity and accuracy of the SCICP.

1.2 Statement of the problem

For children with CP, conducting ADLs may be difficult due to physical and cognitive problems. Self-care is an important ADL and is comprised of a number of tasks namely; eating, dressing, washing and toileting (Westen & Rosenthal, 2003). Accurate assessment of the capabilities of children with CP is needed for realistic intervention (Mailloux *et al.*, 2007). Due to the lack of a valid assessment tool for the South African population regarding children with CP and their ability to perform their self-care activities, Burg (2016) developed the SCICP. Although the item analysis of the tool was completed and content validity was established, no further psychometric analysis of the tool was carried out. The author suggested that a larger sample size of between 35 and 70 typically developing children as well as CP children should be tested. The author stated that in order for the assessment tool to be used for clinical use in the South African context, it is necessary for it to undergo further reliability and validity testing (Burg, 2016).

1.3 Purpose of research study

The purpose of this study is to investigate selected psychometric properties of the reliability and validity of the SCICP for children with CP living in a resource-constrained South African context in order to further the development of the assessment tool for this population.

1.4 Research question

Does the SCICP have adequate known-group validity, components of content validity, internal consistency and diagnostic accuracy for the assessment of children with CP living in a resource-constrained context in South Africa?

1.5 Research aim

The aim of the study is to investigate selected psychometric properties of the SCICP in terms of known-group validity, further content validity, internal consistency and diagnostic accuracy for the assessment of children with CP living in a resource-constrained context in South Africa.

1.6 Research objectives

Objective 1

To determine the known-group validity of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay.

Objective 2

To determine the content validity (response process and relationship to other measures) of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay.

Objective 3

To determine the diagnostic accuracy in terms of sensitivity, specificity of the SCICP for children with CP and typically developing children aged one to six years

Objective 4

To determine the internal consistency of the SCICP for children with CP aged one to eight years

1.7 Significance of the study

The SCICP can serve as a baseline of functioning in self-care activities to be used in goal setting with caregivers of children with CP. This will improve the relevance of therapy as well as assist in measuring the client's success in therapy. By investigating selected psychometric properties of the SCICP, arguments of the tool's reliability and validity may be strengthened for its use in clinical practice in contexts where other assessment tools do not consider the lack of resources and alternate methods used to carry out self-care activities.

1.8 Organisation of the research report

The study consists of six chapters, which describe the process of addressing aspects of the psychometric properties of reliability and validity, namely known-group validity, internal consistency as well as sensitivity, specificity and accuracy of the SCICP. Thereafter, the appendices will be presented.

Chapter 1: Introduction

The introduction describes the importance of participation in ADLs and how occupational therapists (OTs) use intervention to enhance participation. In order to provide appropriate intervention, a thorough assessment using contextually relevant assessment tools, is needed to accurately guide the intervention process for the attainment of goals. It details how the study will aim to establish known-group validity, internal consistency, sensitivity, specificity and accuracy of the SCICP for the purpose of this research study. Thereafter, the problem statement will be analysed followed by the aims, objectives and justification of the study.

Chapter 2: Literature review

The literature review describes the literature around participation and participation constraints associated with CP. It delineates the importance of ADLs for the human experience as well as the lack, and importance, of culturally and contextually relevant assessment tools. The importance of establishing the psychometric properties of assessment tools is explained and the aspects of reliability and validity that will be focused on during this research study are outlined.

Chapter 3: Methodology

The methodology chapter describes the steps taken to complete the study in terms of the reliability and validity testing that took place. The methodology includes a description of the research design used as well as the testing of the procedure followed by the data collection process and, lastly, how the data was analysed will be described.

Chapter 4: Results

The results chapter presents the findings from the scores obtained by the children with CP as well as the typical children on the SCICP. Findings from the two groups' demographic information as well as their SCICP scores were highlighted and compared.

Chapter 5: Discussion

The discussion chapter addresses significant information obtained from the results chapter. Significant findings will be explored and explained using literature. The reliability and validity of the tool, according to the results, will also be explained and described.

Chapter 6: Conclusion

The conclusion chapter presents the conclusions established in the results and discussion chapters. Lastly, this chapter will present the clinical implications of the tool as well as recommendations for future studies.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter reviews the literature regarding the importance of assessment in occupational therapy, the lack of suitable standardised assessment tools for Sub-Saharan Africa, as well as the effect that CP has on a child's functioning. Literature is also reviewed with regards to what constitutes a suitable screening tool and addresses aspects of reliability and validity. Other aspects considered as important constructs to consider when administering an assessment tool for children with CP are; the classification of CP by determining a child's level of functioning with regards to their gross motor abilities, fine motor abilities or hand function, communication and eating and drinking abilities.

Literature was sourced from the following databases: Medline Plus, Pubmed, Science Direct, Cochrane Libraries, Ovid SP and EBSCO Host. The keywords that were used were, 'validity', 'reliability', 'cerebral palsy', 'assessment', 'psychometric properties of assessment tools', 'self-care', 'mobility' and 'hand function'.

2.2 The importance of occupation in occupational therapy

"Occupations are central to a client's (person's, group's, or population's) identity and sense of competence and have particular meaning and value to that client." (American Occupational Therapy Association, 2014: S5). The Occupational Therapy Practice Framework 3rd edition (OTPF III) identifies broad categories of occupations as ADLs, instrumental activities of daily living (IADLs), sleep and rest, work, education, play, social participation and leisure. Occupations have unique features and they are analysed by OTs to ensure that all components of engagement are considered and used effectively as a therapeutic tool and a means to achieve the goal-directed outcomes of intervention (American Occupational Therapy Association, 2014).

The terms *occupation* and *activity* have both been used to describe participation in daily tasks. The OTPF III differentiates between the terms; the term occupation

encompasses participation in multiple activities within the given occupation. Occupations and activities are used as interventions by OTs and the OTPF III states that, “Participation in occupations is considered the end result of interventions, and practitioners use occupations during the intervention process as the means to the end” (American Occupational Therapy Association, 2014: S4). The extent to which a person is involved in a particular occupation is important since occupations contribute to a well-balanced and functional lifestyle. This engagement should be ensured regardless of the amount of assistance clients might need while completing activities. Encouraging a level of independence irrespective of whether clients perform the component activities by themselves or perform the occupation in an adapted or modified environment, use various devices or alternative strategies, or oversee activity completion by others, is essential if they are to be satisfied with their performance in these activities (American Occupational Therapy Association, 2008).

Occupations occur in a specific context and are influenced by a number of client factors, performance skills and performance patterns (American Occupational Therapy Association, 2014). Based on the concepts outlined by the International Classification of Functioning, Disability and Health (ICF), the OTPF III emphasises the focus on everyday areas of functioning and role performance as opposed to impairment (Anaby *et al.*, 2017). Participation is receiving much attention and clinicians are placing a greater importance on the role of the environment in determining participation restrictions. The context and environment are powerful determinants of access to certain occupations as well as the quality and satisfaction that clients have with regards to engagement in these occupations. OTs consider the implications of context on a person’s experience and identity using the concept of “occupational justice” or the right to inclusive participation in everyday occupations regardless of things such as age and ability (Nilsson & Townsend, 2010).

2.2.1 Occupational participation in children with cerebral palsy

This applies to children with CP; in order to facilitate their participation in their daily activities, OTs are concerned with enhancing occupational justice through

therapeutic intervention for those who live in contexts with limited resources and limited access to therapeutic intervention (Saloojee, 2008).

The prevalence of CP in developing countries is considered to be much greater than in developed countries. CP is considered one of the most common causes of chronic disability and one of the most complex conditions which occurs in early childhood (Pashmdarfard, 2017; Gunel *et al.*, 2009; Anaby *et al.*, 2017; Bakuwa, Pilusa and Saloojee, 2020). The variety of associated impairments with CP can significantly limit functional participation of the child (Bakuwa, Pilusa and Saloojee, 2020). In a study conducted in Canada by Anaby *et al* (2017), as well as in an Iranian published study by Pashmdarfard (2017), both studies state that participation is central to a child's development, health, and well-being, and is one of the most important outcomes of rehabilitation intervention for children with CP.

Anaby *et al* (2017) looks at current rehabilitation practices in paediatrics for children with CP. The authors acknowledge that participation of children with physical disabilities is significantly restricted when compared to their typically developing peers. The extent to which participation is integrated into clinical practice is unclear in the work of OTs and physical therapists working with CP children under the age of six years. Based on the findings from the study there was little emphasis on assessment and interventions that focused on participation, leisure and play (Anaby *et al.*, 2017).

Depending on the severity and type of CP, children may be dependent on their caregivers for assistance to perform their ADLs. As CP is a lifelong condition, caregivers will spend a considerable amount of time in caring for their children with CP (Mathye and Eksteen, 2016). Thus, assessment and evaluation of occupations is important if intervention is to result in improved functional independence and increased participation in different life situations. This will also assist with decreasing the burden of care on caregivers (Mathye and Eksteen, 2016).

2.2.2 The importance of assessment in occupational therapy and in children with cerebral palsy

Evaluation, or assessment, is the initial step in the occupational therapy process and is needed in order to understand the activity limitations and participation restrictions that clients have. Thereafter, appropriate outcomes may be developed

for intervention. Successful intervention in occupational therapy leads to enhanced participation in activities, which enhances a person's sense of competence and provides meaning and value to a person's life (American Occupational Therapy Association, 2014). As children with CP experience multifaceted limitations to their participation in ADLs, dynamic and appropriate assessment is needed to formulate and measure appropriate intervention goals (Pashmdarfard, 2017).

Evaluation needs to take place continuously throughout intervention so as to ensure specific outcomes are met. Evaluation is influenced by the therapist's clinical reasoning, the analysis of occupations and through constant collaboration with the client and the client's caregivers. Evaluation includes determining the client's occupational profile and analysing the client's occupational performance. Within the occupational profile, collaboration with the client occurs to ascertain reasons for their seeking out the occupational therapy service, areas of potential occupational disruptions, the context in which occupations are performed as well as identifying supports, barriers and priorities for treatment. An analysis of the occupational performance is specifically concerned with the problems or strengths identified for each client. Performance skills, performance patterns, context, client factors, and activity demands are taken into consideration so that selected aspects can be assessed in detail based on targeted outcomes (American Occupational Therapy Association, 2014).

The evaluation of young children is of great importance to health and educational practitioners so as to mitigate certain factors that may potentially negatively impact a child's development and, thus, participation early in life. However, as stated by Matafwali and Serpell (2014), there are difficulties in implementing appropriate developmental assessments related to occupation in Sub-Saharan Africa as standardised tests have not been developed or aligned to this population. In a systematic review conducted by Donald *et al* (2014) with doctors from twenty-two African countries, these health-care professionals highlighted the need for early identification of CP. Early identification may be assisted by standardised assessments so as to improve basic management approaches for children with CP and their caregivers. Due to the complex interaction that poverty and the limited access to resources has on the management of CP children, there is a need for quick, convenient and cost-effective identification of children who need self-care

intervention (Burg, 2016). Thus, Burg (2016) states that an assessment tool that is standardised and specific to children with CP living in resource-constrained contexts will decrease barriers to assessment of self-care skills of CP children and enhance independence in their self-care abilities.

Children with CP living in resource-constrained areas experience many barriers to accessing adequate health care, further constraining their access to interventions and limiting their independence in occupational performance. An appropriate assessment tool that is able to accurately monitor CP children's self-care abilities may improve access to intervention and provide justification for such intervention. Results from contextually appropriate assessment tools, will assist with favourable goal setting and intervention (Couper, 2002; Burg, 2016; Bakuwa, Pilusa and Saloojee, 2020). In studies conducted in Zimbabwe and Ghana, the authors state that enhanced assessment and intervention programmes for children with CP is one of the ways to assist with decreasing the burden of care on caregivers and effectively improving their quality of life (Mathye and Eksteen, 2016; Klutse and Naab, 2018).

2.3 Contextually relevant assessments tools

Implementation of appropriate programmes to improve early childhood development is dependent on the accurate assessment of development using standardised assessment tools. There is a lack of standardised, valid assessments for use in developing countries. Commonly, available assessment tools from developed countries are used to measure developmental outcomes of children living in Sub-Saharan Africa (Matafwali and Serpell, 2014). The validity of Western standardised assessment tools for Sub-Saharan African populations of children is unknown. Possible discrepancies between these two differing populations may lead to the misinterpretation of results in terms of a child's functioning since the assessment tools may not be culturally or contextually appropriate (Gladstone *et al.*, 2010; Matafwali and Serpell, 2014). Although existing assessment tools may provide some basis for comparison, many test items could be unfamiliar to children living in different environments and test items may have also been poorly translated. This may result in limited validation of the tool on specific populations in other contexts (Geisinger, 1994; Holding *et al.*, 2004; Matafwali and Serpell, 2014).

Furthermore, when assessing children with CP in under-resourced countries, there is a greater prevalence of children born with CP and often the extent of their disability is more severe (Matafwali and Serpell, 2014). Without appropriate screening tools, these children with CP will go unrecognised and, therefore, will not be managed appropriately. Donald *et al* (2015) and Mji *et al* (2017) state that there is a great need for contextually and language specific assessment tools in order to improve service delivery to children with CP in developing countries. These assessments need to be developed with the understanding that people and children living with disabilities in poor communities experience greater barriers in accessing health care services and, therefore, adequate rehabilitation and access to assistive devices (Geisinger, 1994; Donald *et al.*, 2015).

2.3.1 Assessment tools for children with cerebral palsy

The OTPFIII defines ADLs as activities oriented toward taking care of one's own body and are also referred to as basic activities of daily living (BADLs) and personal activities of daily living (PADLs) (Rogers and Holm, 1994). These activities are fundamental to living in a social world; they enable basic survival and well-being (Christiansen and Hammecker, 2008). The OTPFIII includes the following activities under ADLs; bathing, showering; toileting and toilet hygiene; dressing; swallowing/eating; feeding; functional mobility; personal device care and personal hygiene and grooming. For the purpose of the current study, BADLs and PADLs will be referred to as self-care.

The acquisition of self-care in children with CP particularly, is linked with the development of gross and fine motor skills (Gunel *et al.*, 2009). These skills are measured by four classification systems, which have provided a common language to describe CP children's functioning based on client factors of mobility, hand function, chewing and swallowing when eating and communication ability (Paulson and Vargus-adams, 2017).

2.3.1.1 Standardised assessments for classification systems for children with cerebral palsy

The four classification systems for children with CP are the Gross Motor Function Classification System (GMFCS), the Manual Ability Classification System (MACS), the Communication Function Classification System (CFCS) and the Eating and

Drinking Ability Classification System (EDACS). According to Paulson and Vargus-adams (2017), these assessments are standardized, reliable and complementary of one another and can be used cross culturally as they consider the effects of motor and sensory deficits for children with CP. Below, the GMFCS, MACS and EDACS classification systems will be discussed briefly.

The GMFCS was first developed by Palisano and Galuppi (1997) and has five levels; levels I-V. If a child with CP is classified as being on level I they are able to walk without limitation. A child on level II can walk with limitations; which may be limitations with regards to balance or endurance. A child who is able to independently use a wheelchair for longer distances may also be classified on level II. Level III children can walk with a hand-held mobility device inside but may need a wheelchair for outdoor use. A child on this level is able to sit and stand independently and performs transfers independently. On level IV, the child is able to sit with support, but is limited in their ability to be independent in mobility. They often make use of a wheelchair or other wheeled transport. Finally, the level V classification indicates severe limitations in mobility. Head and trunk control is poor and children on this level need complete support with maximum assistance from a caregiver to move around (Paulson and Vargus-adams, 2017).

The MACS specifically relates to the upper limb and is the upper limb equivalent of the GMFCS (Öhrvall *et al.*, 2010). Similarly, it also has five levels of classification. An individual classified on level I is able to handle objects easily, however, there may be some limitations in fine motor coordination. MACS level II children have a lower level of performance when handling objects and may make use of adaptive ways of performing hand function tasks. They are still independent in their daily activities. A child on level III handles objects with relative difficulty and limited success. They require activities to be set up for them. Some activities can be performed independently with the help of the correct adaptations, whereas others require more assistance. MACS level IV requires greater assistance and adapted equipment. A child on this level is unable to complete the task fully independently. Children on MACS level V are unable to handle objects and have severely limited participation in self-care. Simple movements may require maximum assistance (Öhrvall *et al.*, 2010). Lastly, The EDACS assessment looks at the child's ability to

chew and swallow to determine how safely the child with CP can eat without fear of choking or aspiration (Tschirren *et al.*, 2018).

Gunel *et al* (2009) conducted a study with CP children in Ankara, Turkey, at the Hacettepe University between January 2005 and June 2007. Children had a diagnosis of "spastic CP" and were between the ages of four and eighteen years. Children with lower MACS and GMFCS levels, had a greater level of skill in self-care and mobility areas. Self-care skills increased with age in children who were classified on a level I according to the GMFCS and the MACS. Gunel *et al* (2009) suggested a strong correlation between MACS and GMFCS and functional self-care skills. Skill development is dependent on a number of other factors, including the child's cognitive ability, their motivation as well as their attention. A child's environment also plays a large part in the acquisition of functional self-care skills. Skill development is also dependent on the amount of time spent performing the skill. It is important to assess the child's ability to perform self-care skills, however, assessment must take the way these skills are performed across cultures into consideration. Furthermore, children may present with learned compensatory methods, which allow them to be independent in self- care skills.

2.3.1.2 Standardised assessments for self-care for children with cerebral palsy

Independence in self-care is established across childhood and development of basic self-care skills are expected to be complete around seven years old (Öhrvall *et al.*, 2010). For young children, participation in self-care is essential in order to support participation in other life areas such as within school, home and community environments. It is imperative that appropriate outcome measures be used to determine the ability of a child with CP to perform self-care tasks as this will provide a baseline of function in order to set intervention goals. According to James, Ziviani and Boyd (2014), the focus of assessment for children with CP should take a bio-psycho-social approach that aims to enhance the individual's ability to participate in all aspects of life. Children with CP often experience multiple associated difficulties that affect their functioning in self-care. They often fall short of the typical developmental trajectory and may not be as independent as typically developing children (James, Ziviani and Boyd, 2014).

Below is an overview of the existing assessments for the paediatric population that assesses the self-care domain. The name, a brief description, date of publication as well as the reliability and validity of each assessment tool is discussed.

Table 2.1: Brief overview of existing assessment tools for the paediatric population

Assessment tool	Description	Date of publication	Origin of study	Reliability and Validity
The Paediatric Evaluation of Disability Inventory (PEDI)	The PEDI is an assessment tool that was developed in the United States of America for children with disabilities between the ages of six months and seven years and six months old. It is a self-report questionnaire for caregivers of the children being assessed. It is comprised of three sections; the Functional Skills Scale, Caregiver Assistance Scale and a Modification Scale. The Functional Skills Scale assesses the child's ability to perform age appropriate activities within the occupations of self-care, mobility and social functioning (Haley *et al.*, 1992)	1992	United States of America	The PEDI is considered to have strong psychometric properties. The test has internal consistency of α=0,9 and its inter-rater reliability for the self-care domain is 0,84. Test-retest reliability for the self-care domain of the PEDI is 0,98 (Harvey *et al.*, 2008)

Functional Independence Measure for Children (WeeFIM)	The WeeFIM is commonly used to measure rehabilitation outcomes for children with developmental, acquired or genetic disabilities, within clinical and research settings. It is based on the WHO disablement model and was developed in the United States of America. It assesses activities of daily living related to self-care, mobility and cognitive domains through observation. The age range for use of the WeeFIM varies between six months to eight years of age. It can, however, be used on children with developmental disabilities up to the age of eighteen years. It is not possible to use this assessment tool in low resourced settings due to the expensive annual license (James, Ziviani and Boyd, 2014). It would also require adaptation before being used in non-Western settings (Wong *et al.*, 2004).	1994	United States of America	The WeeFIM was originally adapted from the adult Functional Independence Measure (FIM). Content validity was established using eight experts. Construct validity of the self-care domain of the WeeFIM's is r=0,68. When correlated to the PEDI's criterion validity for the self-care domain, r>0,88. The reliability of the WeeFIM shows internal consistency within the motor domain of α=0,,91, inter-rater reliability for self-care is 0,86 and test-retest reliability of self-care ranges between 0,92-0,97 (James, Ziviani and Boyd, 2014).

Activities Scale for Kids (ASK)	The Activities Scale for Kids (ASK) was constructed for use with children with predominantly physical disabilities; in particular, musculoskeletal disorders between the ages of five to fifteen years old. It is a self-report questionnaire with two versions. One version measures a child's capability and the other measures performance. The assessment consists of 30 items, which are representative of self-care, play and mobility domains (Young *et al.*, 2000; Plint *et al.*, 2003). Although the ASK can be downloaded from the internet, there is an annual license fee that also needs to be paid in order to use the assessment. No further training is needed to use the assessment. However, within resource-restricted areas, use of the internet and the license fee are barriers to use of the assessment (Harvey *et al.*, 2008).	1992	Canada	The construct validity of the assessment was determined using Rasch analysis. Construct validity showed divergence of -0,03 and convergence of 0,43. Inter-rater reliability of the ASK revealed a score of 0,99 (Young *et al.*, 2000).
Life Skills Inventory	The Life Skills Inventory is a tool that is designed to assess independent living skills. It was developed in the USA in Washington State by the Department of Social and Health services. It is a non-standardised checklist used to assess an adolescent's level of independence in basic and instrumental activities of daily living. The assessment can be downloaded from the internet and used a number of times (Washington State Department of Social and Health Services, 2000).	2000	United States of America	Non-standardised checklist

Oregon Project - Sixth Edition	The Oregon Project (6th edition) is a non-standardised checklist for children at pre-school age who are visually impaired or completely blind. This checklist forms part of a teaching curriculum for children aged nought to six years old. It covers the following domains; cognition, language, social, vision, compensatory techniques, self-help ability, fine motor and gross motor skills. The self-help section includes self-care items such as eating, dressing, grooming and toileting. It includes teaching material, a skills inventory section as well as a section for references. No additional training is needed to administer the checklist and can be accessed online (Southern Oregon Education Service District, 2016).	2007	United States of America	Non-standardised checklist.
Bayley Scales of Infant and Toddler Development –Third Edition (Adaptive Behaviour Questionnaire)	The Bayley Scales of Infant and Toddler Development – Third Edition (Bayley III) is an assessment tool used to determine developmental functioning of infants and toddlers. This assessment can be used with children between the ages of one to 42 months old in order to determine if developmental delay is present or not. The Bayley-III has also included the Adaptive Behaviour Assessment System- Second Edition (ABAS-II). The Bayley-III assessment comprises sections on cognition, language, motor, socio-emotional and adaptive behaviour subtests. The Adaptive Behaviour Questionnaire has a domain of self-care consisting of 24 items. Further training is needed to be able to administer the Bayley-III. There is also a cost involved in acquiring the assessment. Additional training and the cost of acquiring and administering the assessment make it impractical for use in a resource-constrained setting (Albers et al., 2006).	2006	United States of America	The ABAS-II has standardisation properties separate to those of the Bayley-III. Internal consistency, of the ABAS-II ranges from 0,79 to 0,98 using the coefficient alpha. Test-retest reliability shows coefficients of 0,80 and higher. Inter-rater reliability for the adaptive domain is 0,79 and for the adaptive skills area, 0,73. Validity shows moderate correlation between the ABAS-II and the Vineland Adaptive Behaviour Scale – Interview Edition with scores ranging between 0,58-0,7 (Albers et al., 2006).

The Primary Progress Assessment Chart of Social Development	The Primary Progress Assessment Chart of Social Development is a checklist of social development for children and adolescents with intellectual disabilities. The assessment contains domains of self-help, communication, social aspects and occupation The self-help section includes self-care skills such as eating, toileting, washing and dressing (Gunzburg, 2012).	1963	United Kingdom	The Primary Progress Assessment Chart of Social Development is an old assessment and is out of print, and is, therefore, not easily accessible. It has validity of 0,42 when compared with the Stanford Binet Test for self-help. Its reliability score for self-help is 0,95 (Gunzburg, 2012).

The assessments described in the table above have been used for either research purposes or within clinical settings for children with disabilities. These assessments, however, are not specific to CP and have all been developed in more affluent, well-resourced Western countries such as the United States of America, the United Kingdom and Canada. This is a limitation and a barrier to using these assessment tools effectively within the South African context as they are not standardised for a non-Western population. The adaptability of these assessments is limited. They are not contextually relevant to South Africans living in resource-constrained areas whose home language is not English, present with lower levels of education and have limited access to health services. Thus, results from these assessments may prove invalid. Furthermore, many of the abovementioned assessments have a cost involved either in purchasing the assessment tool, or obtaining additional training to be able to administer the assessment. Within resource-constrained contexts, there is not adequate funding available to be able to purchase and administer costly assessments or to attend trainings.

The PEDI for instance is considered the gold standard assessment for assessing the occupational performance areas of self-care, mobility and social participation in children with a disability. However, this assessment is not specific to children with CP, and the efficacy of the tool for the South African context is unable to be established as the publishers of the PEDI have refused to allow the tool to be translated into isiZulu (Burg, 2016). Although the functional classification systems are widely used as a resource for assessing CP children's functioning, Burg (2016) states that appropriate and standardised occupational performance assessments are needed to supplement these classification systems in order to provide a holistic picture and understanding of the CP child's overall functioning. There are currently no standardised assessment tools that are available freely to assess the self-care abilities of children with CP living in a resource-constrained and low socio-economic context in South Africa.

2.3.1.3 Assessment tool for activities of daily living for children with cerebral palsy developed in South Africa

Burg (2016) identified a need within current occupational therapy practice in South Africa for contextually appropriate occupational performance assessment tools to be developed. This is necessary to accurately establish areas of a client's

functioning that require intervention. She stated that this would improve intervention and allow for the comparison of evidence-based intervention outcomes. The author found that available tools for assessing self-care in children with CP living in resource-constrained areas were not contextually or culturally sensitive. She then developed the SCICP to assess the ability of CP children living in the South African context to perform their self-care tasks.

Burg (2016:4) states, *"*There is a need for a valid and reliable tool to measure both the level of dysfunction in occupational performance and the change in occupational performance in children with CP living in resource-constrained South African settings…(these) children have little access to resources and services. Thus, if service delivery and evidence-based treatment is to be offered, a valid outcome measure appropriate to their context, is required. The new self-care assessment tool, if validated in South Africa, can be used clinically and for research for children with CP in similar settings". The SCICP aims to assess ADLs, as defined by the OTPIII and the ICF. In addition to these self-care tasks, it also aims to assess functional mobility associated with each self-care task as well as functional mobility associated with sleeping.

Burg (2016) based the assessment of the reported self-care skills of typically developing children and children with CP between the ages of nought to five-years-old living in a poorly resourced area in KwaZulu-Natal province. In developing this tool, she hoped to eliminate test bias and misleading results in this population. A number of the steps of instrument design were followed to develop the SCICP as set out by Davis and Morrow (2004). These include: defining the construct and domains, writing test items and reviewing test items. Item selection and content validity of the SCICP was established using subject matter experts (SMEs) and expert caregivers. This author did not complete reliability testing or item analysis nor did she conduct norming studies. Only content validity in terms of the content of the items was previously established with both subject matter experts (SMEs) and end users for the SCICP (Burg, 2016). However, Burg's study is a starting point for the construction of a useful and meaningful assessment tool for the South African context.

The SCICP was based on a review of existing standardised assessment tools that measure self-care in children with and without disabilities. Items were based on this review and were then analysed and underwent test definition, construction, item preparation, planning, revision and finally, analysis of the content validity. The results from the study indicated that the SCICP is able to determine the actual self-care performance of children between the ages of two to five-years-old on all of the test domains. Items on the SCICP are presented sequentially according to typical developmental milestones that are achieved in each area of self-care. Caregivers are expected to complete the assessment for each domain representing a different area of their child's self-care abilities. They are required to start the completion of the assessment from the first item in that domain. The child is given a score of either one, two, three or four for each test item for each domain.

The caregiver can indicate whether the child scores a one, which will indicate the child's complete dependence with regards to that particular self-care test item, a two would indicate that the child requires a lot of assistance from the caregiver to complete the self-care task, a three indicates that the child requires only a little assistance from the caregiver in order to complete the task and a four demonstrates that the child is independent in that particular self-care task. The older the typically developing child is, the higher the score the child will achieve for the test items in each test domain and overall. Younger typically developing children will achieve lower overall scores due to the fact that developmentally, they are not yet able to reach certain milestones.

In Burg's (2016) study, one of her objectives was to develop the SCICP and its test items. Her small sample of five typically developing children's scores were compared to the five CP children of similar ages. Test results showed a difference in these scores. The scores from the SCICP provide information regarding the child's level of independence in their self-care activities. As the SCICP test items are organised according to typical developmental progression, whether a child scored a one, two, three or four for a particular test item, determines what self-care tasks the child can perform and to what extent. Burg (2016) noted that the higher the scores on the SCICP were, the older the typically developing child was. This indicates developmental progression.

Burg (2016) points out that several factors need to also be considered when assessing CP children's self-care skills, namely; age, hand function, cognition, classification levels and other associated impairments. However, the SCICP still allows for the performance of ADLs in CP children to be scored, irrespective of their chronological age. These scores can then be measured and compared against typical developmental performance on the SCICP. What Burg's (2016) initial field testing highlighted, is that the SCICP was able to determine a child's ability to perform their self-care tasks as well as highlighting a difference in test scores between typically developing children and children with CP of similar ages. However, due to Burg's (2016) small sample, inferences based on typical or CP children's performance on the SCICP cannot be made. A guide for interpretation of the scores will only be able to be conducted once the SCICP test has proven reliability and validity on a larger population.

Once the evaluation phase is completed using validated assessment tools, goals for intervention may be developed using the Goal Attainment Scaling (GAS) method. This method includes the client in the goal setting process. In the case of the SCICP, the caregivers of children with CP, and if possible, the children with CP themselves, would be involved in the goal setting process. Mailloux *et al* (2007) states that intervention goals should be based on functional aims and represent an area of the child's occupational performance that is important to the child and the family. Goal development ensures that therapy is client-centred, relevant and meaningful to children and their families.

2.4 Properties of screening assessment tools

The development of instruments for the assessment of skills related to the context of a population requires research to be done on a representative sample of that population. This will ensure careful selection of appropriate test items for the population. Systematic validation of assessment items needs to be conducted so that test items are responsive to aspects such as cultural and linguistic diversity (Matafwali and Serpell, 2014). Glover & Albers (2007) suggest three different approaches when planning to use assessment tools for other populations, namely: adoption, adaptation and assembly.

Adoption relates to a direct transfer of an already existing assessment tool from its cultural context onto another. Although convenient, the probability of bias is high and changing the tool for another culture can make it invalid. Adaptation of a test requires the modification of test items as well as administration instructions and response options. The aim of this process is to produce functional equivalence and ensure adequate translation of the assessment tool so as to enhance cultural appropriateness (Matafwali and Serpell, 2014).

Lastly, assembly involves the development of a new tool in order to accommodate for cultural and contextual differences and decrease test measurement bias. Not only does the target population need to be taken into consideration when developing a new assessment tool, but three other key components are also needed; appropriateness, technical adequacy and usability (Matafwali and Serpell, 2014).

The first key component needed in order to develop a new assessment tool is that of appropriateness. Appropriateness for intended use implies that the tool is specific for administration in the context for the selected purpose. It should be compatible with local service delivery needs, there should be alignment with constructs of interest and have theoretical and empirical support as well as population fit. When determining whether the tool is compatible with local service delivery needs, the assessment tool should predict future problems of the individual and highlight difficulties that the individual currently experiences. With regards to population fit; the tool should be contextually and developmentally appropriate (Glover and Albers, 2007). The second component that needs to be considered during assessment tool development is the adequacy of the technical aspects associated with screening tool standardisation. Adequacy of technical aspects considers the appropriate standardisation of the screening tool for use on the population it is targeting. The tool should consistently measure what it is intended to measure and provide accurate identification of those persons at risk. Another technical aspect is the adequacy of norms. Norms for the target population should be representative of individuals that the assessment tool intends to measure based on specific inclusion criteria. In addition to this, there needs to be an appropriate sample size.

Lastly, Glover and Albers (2007) state that an assessment tool should have usability. The authors' state six important considerations when determining the

usability of a tool within a certain context: there should be minimal cost involved when administering the tool and the administration of the tool should be feasible. Feasibility of the tool also considers the time taken to administer the tool. The tool should be appropriate to the context as well as provided with simplified and clear instructions on how to administer the tool. If possible, the tool should be acceptable to multiple stakeholders and there should be appropriate infrastructure for the collection, management and interpretation of the assessment data. In addition to this, there should be suitable administration; scoring and interpretation instructions provided if the language of the assessment tool is different to that of its target population. Finally, information gained from completion of the assessment tool by stakeholders should be useful to them and result in improved treatment outcomes (Glover and Albers, 2007).

During the initial piloting phase of the SCICP, it was found that the tool adhered to the abovementioned criteria and to four other standards used for the development of a screening test as described by Glover and Albers (2007). The SCICP was compatible with local service delivery needs and was appropriate for the context. The assessment tool was aligned with constructs of interest, based on theoretical and empirical constructs, and had population fit. In terms of usability, the tool was low in cost to administer. Administration of the tool was feasible and could be completed in an interview or caregiver report format in the home language of the caregiver of the child. This made the tool acceptable to the stakeholders involved.

When developing a screening tool, reliability and validity need to be considered. Whereas reliability of a tool ensures that measurement is consistent, validity of a tool ensures that assessment is accurate (Glover and Albers, 2007). Aspects of the reliability and validity of the SCICP need to be determined to establish if the assessment tool will enhance treatment utility and technical adequacy. Thus, the technical adequacy of the assessment tool should be confirmed to ensure it is standardised appropriately for its target population. It should also be consistent in its measurement and accurately identify individuals at risk of developmental delay. This includes determining the adequacy of norms, which considers the sample's representativeness, how recent the results are and the sample size. Furthermore, the reliability and validity of the SCICP should also be determined before the tool

will be acceptable for clinical use as a standardised assessment (Glover and Albers, 2007).

2.5 Defining assessment tool reliability and validity

James, Ziviani and Boyd (2014) state that it is important for therapists to assess ADLs with rigorous assessments that are reliable and valid. These assessments should be specifically validated for the population with which they are intended such as children with CP from a similar context to ensure that intervention goals are developed in line with assessment results and are relevant to the client (Mailloux *et al.*, 2007; Harvey *et al.*, 2008; James, Ziviani and Boyd, 2014).

Standardisation of an assessment tool is crucial to its development and use in the clinical setting. Two aspects of standardisation of a tool occur when its reliability and validity are enhanced. As stated by Glover and Albers (2007) reliability ensures consistent measurement. Reliability can be impacted by a number of factors, for example, test characteristics such as test length, item type, item quality and item difficulty and circumstances of administration such as the physical conditions of testing, the instructions, the proctor and the time limit (Glover and Albers, 2007). Lastly, the respondents can also influence reliability in that they need to be from homogenous groups to ensure less variance (Traub and Rowley, 1991).

The types of reliability, as outlined by Davis and Morrow (2004) are test-retest reliability and internal consistency. Test-retest reliability can be determined by stability coefficients and internal consistency can be deduced by the split half-method or the coefficient alpha (Davis and Morrow, 2004). Internal consistency explains the relationship between test items and the extent to which items on the test are measuring the same thing. It can be estimated after one administration of the test and, therefore, the test needn't be administered over multiple time periods (Bolarinwa, 2015). If the relationship between test items is strong, this strengthens the internal consistency, or homogeneity, of the assessment tool. In addition to this, if the tool is designed to measure a specific construct then all test items should have a strong connection with the construct being measured (Bolarinwa, 2015).

The Cronbach's coefficient alpha is more often used during scale development with items that have several response options, for instance; 1= strongly disagree to 5=

strongly agree (Bolarinwa, 2015).To determine the coefficient, or Cronbach's, alpha, a computer programme using statistical analysis software can be used; the higher the reliability value, the more reliable the measure. The reliability coefficient (alpha) can range from zero to one. Zero represents a questionnaire that is not reliable and one represents an absolutely reliable questionnaire. Nunnally and Bernstein (1994) state that research should aim for reliability values of 0,7 and above.

The authors noted that reliability values increase as the test length increases; the more items used in the test to measure the construct of interest, the more reliable the test becomes. However, participants are often reluctant to fill in lengthy questionnaires. Therefore, a well-developed, yet brief test, will lead to increased levels of participant responsiveness as well as comprehensive answering of the research question. It is important to note that conditions that could affect Cronbach's alpha values are as follows: the numbers of test items and timing, among others. With regards to the number of test items, normality increases Cronbach's alpha value, while skewed data reduces it. Whereas timing can also affect Cronbach's alpha. Cronbach's alpha does not indicate the stability or consistency of the test over time (Bolarinwa, 2015).

Messick (1995: 741) defines validity as, "… an overall evaluative judgment of the degree to which empirical evidence and theoretical rationales support the adequacy and appropriateness of interpretations and actions on the basis of test scores or other modes of assessment". According to Davis and Marrow (2004) there are four aspects of validity, they are; content, construct, generalisability and consequential validity. Construct validity, as defined by Bolarinwa (2015:3) is "… the degree to which a tool measures the trait or theoretical construct that it is intended to measure". According to Bolarinwa (2015) this is the most important, as well as the most challenging, measure of validity to investigate. Construct validity determines how meaningful the tool is in practical use. There are five types of evidence used to establish construct validity; namely, convergent validity, discriminant validity, known-group validity, factorial validity and hypothesis-testing validity. For the purpose of this study, known-group validity of the SCICP will be investigated.

Known-group validity is used when one group has established attributes of the outcome of the construct and is compared with a group where the attribute is not

yet known. Bolarinwa (2015) states that the measured construct is expected to be higher in the group with the related attribute and lower in the group with the unrelated attribute. For example, a questionnaire used to identify a condition in clients will administer the questionnaire to clients who have a clinical diagnosis of this condition and administer the same questionnaire to those without a diagnosis. According to known-group validity, it is anticipated that the construct identifying the condition in the questionnaire will have a significantly different score for clients with the condition as opposed to those without the condition (Bolarinwa, 2015).

Diagnostic accuracy based on sensitivity and specificity can be used to predict how abnormality or normality is indicative of particular test results (Deeks and Altman, 2004). Sensitivity correctly identifies, in this case, children with CP and developmental delay. Specificity of the test shows that it will not identify typically developing children without a developmental delay (Deeks and Altman, 2004). Sensitivity and specificity of a test can be combined to provide likelihood ratios. Likelihood ratios have been said to be more useful than sensitivity and specificity as they provide further information regarding the probability of observing the specified result in clients with and without the disease. They provide information regarding how many more, or less, times clients with the disease are likely to have a particular result than clients without the disease. These ratios enhance the usefulness of diagnostic, or screening tests (Akobeng, 2007; Mandrekar, 2010).

2.6 Summary

The first step in the occupational therapy process, evaluation, is critical so as to correctly determine the client's needs for appropriate intervention. Evaluation needs to not only be based on accurate assessment, but also consider the collaborative effort of determining goals with the client and their caregivers. Most assessment tools have been standardised in developed countries, thus, allowing for bias when using these same tools on populations from developing countries. Assessment tools are often not culturally or linguistically appropriate and do not provide accurate assessment results.

CP is a neurological condition, which affects a large percentage of children living in Sub-Saharan Africa. CP can be the cause of considerable disability due to its associated co-morbidities, which, among others, affect a child's movement,

cognition, hand function and the ability to eat and drink. The ability to carry out self-care tasks is essential to support competence in activities in other life areas. A lack of appropriate assessment tools means that deficits in many children with CP will not be appropriately assessed and monitored and will, therefore, not be managed appropriately. Burg (2016) recognized the need for a culturally appropriate tool for the assessment of CP children's self-care tasks within the South African context so as to enhance the intervention outcomes of these children. She followed a number of steps as laid out by prominent researchers. Important aspects of screening tool design were investigated such as technical adequacy, appropriateness for intended use and usability.

The study by Burg (2016) created the SCICP and aimed to establish the tool's content validity. She stated that further reliability and validity testing was necessary so as to use the tool for clinical use in the South African setting. The reliability and validity of a tool is imperative to determine if the tool is accurate in identifying deficits in self-care in children with CP living in resourced-constrained contexts. Furthermore, certain characteristics of a CP child's functioning also need to be taken into consideration based on the classification systems used for children with CP when considering a child's ability and potential to perform their self-care tasks.

CHAPTER 3: METHODOLOGY

3.1 Introduction to methodology

This chapter describes the research methods that were used to determine aspects of the SCICP's reliability and validity.

3.2 Research design

A descriptive quantitative, cross-sectional study design was used. This non-experimental design was used to determine known-group validity and internal consistency of the SCICP as well as the tool's sensitivity and specificity. The assessment scores of a group of children with CP, an established attribute affecting the outcome of self-care, were compared to a group of typically developing children. A cross-sectional study design is useful in resource-constrained environments as they are quick and inexpensive to administer. They can be used to analyse relationships of various factors in a particular group, and seek to highlight associations between groups. Populations or subgroups can be described using a cross-sectional design, understand prevalence and the impact of certain outcomes or risk factors on a population (Pandis, 2014; Zangirolami-Raimundo, Echeimberg and Leone, 2018). The disadvantages of this study design is that it can be prone to selection and information bias and can have confounding results (Pandis, 2014).

The study design was quantitative as numerical data were collected and descriptive statistics were used in that no variables were manipulated. A cross-sectional study design in which data were collected at one point in time was chosen as it allowed the researcher to access a variety of children with CP and a variety of children who were typically developing. Data with the aforementioned variation allowed for greater quantification of data with the required number of participants. Once data had been quantified, it was then used to determine differences among study groups according to age. As this was a descriptive study where causal direction was not established, a cross-sectional design was appropriate (Bryman, 2012). The cross-sectional design provided strong external validity and had the advantage of replicability as a result of the specified procedures (Bryman, 2012).

The study design had a comparative element where variables were correlated to determine a relationship between them to further confirm the response process and relationship to other variables of the SCICP (Bryman, 2012). In terms of reliability, validity, replicability and generalisability, comparative studies are the same as a cross-sectional study.

3.3 Site of research

Data were collected at Tambo Memorial Hospital (TMH) in Boksburg by recruiting caregivers of children with CP who form part of the CP clinic run by the multidisciplinary team (MDT). The caregivers of the children who attended the paediatric outpatient department at the hospital were recruited for the typically developing children. Further data were collected at Thelle Mogoerane Regional Hospital (TMRH) at the Occupational Therapy Department. These hospitals are two of the six public sector hospitals that serve 3 379 104 people in the communities in the Ekurhuleni districts. This district supports a population across various socio-economic groups with 20% living in informal housing. Unemployment is at 29.3% (Global Africa, 2018). The Ekurhuleni Metropolitan Municipality forms the local government of the East Rand and is one of six districts in Gauteng province. It is made up of nine towns: Germiston, Alberton, Benoni, Boksburg, Brakpan, Kempton Park or Tembisa, Edenvale, Nigel and Springs (Marutlulle, 2017).

Ekurhuleni district has an extensive total surface area of informal settlements; 1928 square kilometres with a population of 3.2 million people and 896 117 households. These are extremely densely populated areas with predominantly temporary type structures comprised of basic materials. Informal settlements usually lack at least one condition that constitutes basic housing, namely, adequate sanitation, durable housing and adequate living space. Many informal settlements are subject to hazardous conditions such as unfertile grounds, along rivers or canals and are in areas prone to floods or sewage due to improper sanitation or close to dump sites with limited access to waste removal (Ekurhuleni Metropolitan Municipality, 2016; Marutlulle, 2017).

Marutlulle (2017) outlines that informal settlements or squatter camps have defining characteristics that can be physical, social and legal. Physical characteristics of informal settlements state inadequacy of basic services such as water, sanitation,

electricity, roads and drainage. It also implies a lack of schools, health centres and market places. In terms of social characteristics, informal settlements refer to the fact that squatters may be migrants, rural-urban or urban-urban. Legally, people living in informal settlements lack ownership of their land.

The CP clinic at TMH takes place every Wednesday morning from 08:00 to 12:00. There are four groups of CP children that take part in the CP clinic. Each group, therefore, attends the clinic once a month. The children are divided into groups based on their level of functioning; predominantly, the children's GMFCS level is taken into consideration as well as their cognitive ability and behavioural needs when being placed in the appropriate group. The CP clinic at TMH was recently revamped by partnering with the non-profit organisation Malamulele Onward (MO). With mentoring from the organisation, TMH has implemented their therapy programme since the beginning of 2018 and adapted it slightly to suit the setting. A Parent Facilitator, trained by MO, who is also the mother of a child with CP, assists with the implementation of the clinic. She runs the first two hours of the clinic, which is centred on education regarding the theme for the month. After a short tea break, the MDT provides therapeutic intervention and education to the caregivers based on the topic covered by the Parent Facilitator that morning.

At TMRH they have two different services for children with CP at the hospital. A CP clinic, similar to that of TMH, runs every Friday morning from 08:00 until 12:00 and they also have individual client appointments that last for approximately 45 minutes throughout the rest of the week. Children who attend the clinic on a Friday are often more severely disabled and have higher GMFCS and MACS levels. The children who attend the individual appointments have lower GMFCS and MACS levels and are less disabled. The MDT runs the CP clinic and also has an element of caregiver education followed by therapeutic intervention by the MDT.

TMH is a regional hospital in Boksburg and TMRH is also a regional hospital located in Vosloorus, which is the largest township located south of Boksburg and east of Katlehong. TMH and TMRH are the largest hospitals in the district and many people access health care services provided by these two hospitals and TMH was convenient for the researcher as she works at this hospital. Thus, these two sites were chosen for convenience and for the fact that they both have established CP

clinics that provide therapy to many CP children every month. The CP clinics that are run at TMH and TMRH provide therapeutic services to approximately 60 and 70 children and their caregivers respectively. At TMH and TMRH, CP children account for the majority of paediatric conditions seen in one month at the Occupational Therapy departments. The majority of caregivers and their children live in informal settlements in the Ekurhuleni district. Participants chosen for the study were predominantly from a low socio-economic status and spoke either isiZulu or Sesotho.

3.4 Population and sample

The caregivers of typically developing children who attend the Paediatric Outpatient Department at TMH for routine check-ups were recruited for the typically developing group. Available caregivers of typically developing children between six months and six years and six months (the age range covered by the SCICP) were recruited and invited to participate in the study. The second group were the caregivers of children with CP between six months and eight years and six months who receive therapy from the CP clinic at TMH, or attend individual appointments at TMRH. It was necessary to increase the age range of the CP group as many children who form part of both TMH and TMRH CP clinics were over the age of six. Most children in the CP clinics were also severely disabled and fell behind the typical developmental trajectory for their age group. Thus, the age range for the CP children was extended so as to include more CP children in the study. Convenience sampling was used in order to identify suitable participants. Five typically developing children from TMH and five children with CP who attend the CP clinic at TMH were recruited for the researcher to observe their performance on selected items of the SCICP. These observations formed part of the pilot study.

The children who form part the TMH CP clinic are allowed to attend the clinic for two years. This ensures that children and their caregivers receive therapy and training through the provision of the CP programme twice before being down referred to a clinic in their community. If children are not compliant with regular attendance, for example, attend only three CP clinics in one year, caregivers are contacted to find out the reason for non-compliance. Once the reason is determined, they either continue receiving therapy at TMH for the two-year cycle or are down referred to

their local clinic. At TMRH, children are allowed to remain in the clinic for as long as their caregivers can bring them to the hospital. CP children are down referred if this is the caregiver's request. When the CP children reach the age of six-years-old, if possible, school placement is facilitated by both hospital's therapists.

3.4.1 Inclusion criteria

Caregivers of children without CP whose children have:

- No reported disability
- Six months to six years and six-months-old when typically developing children achieve the maximum scaled score (100) in the PEDI self-care domain (Haley *et al.*, 1992)
- Confirmed as typically developing in their hospital file and attending routine check-ups for immunization or minor illness
- Home language is isiZulu or Sesotho

Caregivers of children with CP whose children have:

- Various levels of severity based on the GMFCS and MACS classification confirmed by an experienced OT or physiotherapist.
- A confirmed diagnosis of CP by a doctor at TMH
- Attend TMH paediatric outpatient appointments for check-ups as well as the CP clinic on a monthly basis
- Attend the CP clinic, or individual appointments, at TMRH
- Home language is isiZulu or Sesotho
- Six months to eight years and six-months-old when children at MACS level I may achieve a scaled score of 100 in the PEDI self-care domain (Öhrvall *et al.*, 2010)

3.4.2 Sample size

Based on the greatest number of items (25) in the dressing domain in the SCICP according to 90% of studies reviewed, a participant item ratio of two for newly-developed client reported outcomes measures was required. Therefore, a sample of 50 participants in the group of typically developing children and a sample of 50 children with CP will be recruited. The sample was to be stratified so that there were

eight to nine children in each age group by year for the children between nought years to six years and six-months-old (Anthoine *et al.*, 2014).

3.5 Measurement instruments

3.5.1 Demographic questionnaire

The demographic questionnaire was developed by the researcher and conducted as a self-administered questionnaire with the caregivers of typically developing children and the caregivers of children with CP (Appendix A). Questions included information regarding the child's medical information, birth and developmental history as well as social circumstances. Other questions related to socio-economic status indicators such as access to household water and electricity, if the caregiver was employed or not and if the child received any kind of social grant. For the children with CP, additional information regarding the child's GMFCS level and MACS level was requested and filled in by the researcher or the research assistant at TMH and TMRH. The CP children's GMFCS and MACS levels need to be considered in relation to the child's ability to perform his or her self-care abilities. It was also asked of the caregivers if the child had epilepsy or a visual or hearing impairment.

Caregivers of the typical and CP children received the same demographic questionnaire. In cases where the demographic questionnaire only applied to CP children, or if an item needed to be filled in by the researcher, this was indicated on the form.

3.5.2 Self-Care Inventory for Children with Cerebral Palsy

3.5.2.1 Caregiver report or interview with caregiver

The SCICP is a caregiver report, or self-administered, questionnaire that caregivers completed to indicate the extent to which their children could perform their self-care activities independently (Appendix B). The self-care domains as well as the number of test items included in each domain are as follows: eating (19), functional mobility associated with eating (10), dressing (23), functional mobility associated with dressing (2), washing (10), functional mobility associated with washing (8), grooming (9), functional mobility associated with grooming (2), toileting (5), functional mobility associated with toileting (9), mobility related to sleep (3) and

general mobility (9). The format required the respondents to tick the responses in blocks on a scale of one to four. Caregivers provided answers that indicated if the child could perform the self-care activity independently (4), with a little assistance (3), with a lot of assistance (2), or not at all (1). The assessment form was provided in English, isiZulu and Sesotho translations. The questionnaire can be administered as an interview if the caregivers require assistance with the questions.

3.6 Research procedure

Ethical clearance was obtained from the Human Research Ethics Committee at the University of the Witwatersrand (Appendix C), and permission was obtained from the CEOs at TMH (Appendix D) and TMRH (Appendix E).

3.6.1 Translation of the Self-Care Inventory for Children with Cerebral Palsy

The SCICP was available in English and isiZulu but not Sesotho, a language commonly spoken in Gauteng where the research took place. The head of the Occupational Therapy department at TMH translated the SCICP as well as all the other research forms, as her home language is Sesotho. She has more than 10 years of experience as an OT and is familiar with the terminology in the assessment form. The Parent Facilitator at TMH's CP clinic, who was also the research assistant during the study, did back translation of the SCICP and the other research forms once it had been translated into Sesotho. Her home language is Sesotho and she completed her Matric with the subject Sesotho as her home language. She has also worked as a Parent Facilitator for MO for three years. The research assistant discussed each item on the SCICP with the researcher to ensure that the meaning of the item was the same as in English. A qualified isiZulu teacher translated the research forms, other than the SCICP. She received her Higher National Diploma in Education from the University of Zimbabwe and has been teaching isiZulu since 2010. The same translator did back translation of the research forms.

3.6.2 Training the research assistants

The data collection of the SCICP for children with CP and typically developing children required that the researcher make use of two research assistants. These were the Parent Facilitator at the TMH CP clinic and the Grade 1 OT at TMRH. The

Parent Facilitator was trained in administering the SCICP by verbally going through the form with the researcher before testing the SCICP on a typically developing child during the pilot study phase. The pilot study served not only as a means of testing the procedure, but also as an opportunity for the Parent Facilitator to administer the SCICP with the help of the researcher before data collection commenced. In order to train the Grade 1 OT at TMRH, a telephonic conversation took place. During this phone call, the researcher went through the SCICP and all other research forms with the therapist. The research procedure was explained verbally to the OT at TMRH on how to administer the questionnaire and how to assist the caregivers should they have any questions regarding the completion of the questionnaire.

3.6.3 Pilot study

The research data collection procedure was piloted from start to finish with a mother of a typically developing child in order to assess the content of the demographic questionnaire and the acceptability of the SCICP. The purpose of the research was briefly explained to the mother, as well as the consent forms that she needed to fill in. The research assistant observed how the research study was explained to the caregiver of the child and how the researcher showed the mother each form and what its purpose was.

Once the mother had finished reading the information sheet, she was asked if she had any questions and if she had understood the information sheet. She was asked if she thought there needed to be any changes made to the information sheet. The mother indicated that she understood everything and that no changes needed to be made. She was then asked to read and complete the consent form. Thereafter, the mother completed the demographic questionnaire. The researcher and the research assistant were present at all times if the mother needed assistance in order to complete the demographic questionnaire.

Lastly, the mother of the child completed the SCICP independently. She was told that she could ask the researcher or research assistant questions at any time during the completion of the form. The manner in which the form was laid out was explained to the mother as well as how to score it using the Likert scale. The mother was able to complete the SCICP independently. After the pilot study had been completed, the researcher thanked the mother for her participation.

Five typically developing children from TMH and five children with CP who attend the CP clinic at TMH were recruited for the researcher to observe their performance on selected items of the SCICP. The SCICP can also be used as a guide for observation of a child's ability to perform self-care tasks. The therapist can use observation to further evaluate the response process to confirm content of the assessment items (Sullivan, 2011). The therapist may observe a few specifically chosen items related to the caregiver report to provide a holistic understanding of the child's ability to perform their self-care tasks.

After administering the SCICP to the caregiver, the child can be observed performing a number of activities that required hand function as well as functional mobility associated with a dressing task. The caregiver report was then compared to therapist or research assistant observations to determine the correlation between the scores. When the tool is used in practice, this will need to be done with larger numbers of children and their caregivers.

3.6.4 Stratification of the sample

The sample was to be stratified so that that there would be eight or nine children in each age group for both the CP and typically developing children. This, however, did not occur for all age groups in each sample group. The reason for this is that there were not enough children available in each age category at the CP clinics and individual appointments at TMH and TMRH. The ages of the typically developing children who attended the paediatric outpatient clinic at TMH could also not be controlled. It depended on the children that were available at the hospital on the days of data collection and as many caregivers did not agree to participate it was not possible to achieve a stratified sample.

3.7 Data collection

3.7.1 Caregivers of typically developing children

The caregivers of typically developing children were recruited to complete the assessment form on their child at the Paediatric Outpatient Department at TMH. All caregivers recruited into the study were provided with an information sheet regarding the study (Appendix F) before completing the demographic questionnaire and the SCICP. If the caregivers agreed to participate in the study the child's file

was checked with the caregiver's permission to exclude any children that did not meet the inclusion criteria. A large number of caregivers were unwilling to participate in the study making it difficult to obtain a stratified sample of typically developing children by age.

Data were collected through means of caregivers completing the demographic questionnaire and the SCICP for their child. The demographic questionnaire and SCICP were provided in English, isiZulu and Sesotho translations and the research assistant at TMH was available to assist caregivers with the completion of the SCICP if they were unable to read or write or had any questions about the data collection forms. The data collection process for the typically developing children took approximately three months to complete, from the middle of May to the end of July 2019.

3.7.2 Caregivers of children with cerebral palsy

Data collection took place at TMH with the caregivers of children with CP who form part of the CP clinic database seen at the Occupational Therapy Department by the MDT. Data collection at TMH started in the middle of May 2019 and ran until the beginning of August 2019. All caregivers recruited into the study were provided with an information sheet regarding the study (Appendix F) and were asked to sign a consent form (Appendix G) before completing the demographic questionnaire and the SCICP. Data was collected during the tea break or after the clinic had finished at 12:00 so as not to impact the therapy the child and the caregiver received. A container was available for caregivers to place their completed consent forms, demographic questionnaires and SCICP in once they were finished.

Although data collection took place at TMH's CP clinic over a period of three months, there were not enough participants available to achieve the sample size. Changes were made to the inclusion criteria. The age of children with CP was increased to eight years and six-months-old, as many of the children who attend the CP clinic at TMH were older than the age of six years and six-months-old. This increase in the age range still allowed caregivers to indicate the child's self-care ability on the SCICP due to the fact that children with CP develop at a slower rate than typically developing children (James, Ziviani and Boyd, 2014). The recommendation to use

CP children older than the age of six years and nought-months-old was also made by Burg (2016) in her study.

Due to the small sample size that was collected at TMH, the researcher approached TMRH in order to gain access to the children attending their CP clinic and individual outpatient services. After receiving permission, the Grade 1 OT at TMRH was trained in how to administer the SCICP. Thereafter, the OT recruited the caregivers of children with CP who form part of their individual outpatients, as well as the CP clinic clients and their caregivers. After the CP clinic finished at 12:00 on Fridays, caregivers were asked if they would like to take part in the research study. If they consented, the Grade 1 OT asked caregivers to sit in a circle and she was available to assist them with the completion of the form as they filled it in. This OT also completed the SCICP with caregivers of the CP children who attended individual occupational therapy appointments in the Occupational Therapy department. She administered the research questionnaires to the CP children's caregivers and made use of another staff member to assist with explanations of the forms in isiZulu or Sesotho if necessary. This data collection phase took place from the end of August until the middle of October 2019.

3.7.3 Observation of typically developing children and children with cerebral palsy

Ten caregivers at TMH were asked to sign informed consent for their child to take part in the study and were asked for permission for the dressing activities that their child would perform to be photographed (Appendix H). Children were asked for assent to complete the dressing tasks in their home language (Appendix I). Convenient sampling selection took place for the children that were observed.

Response process of the data was confirmed by the observation of five typically developing children and five children with CP between the ages of two to eight years old performing dressing activities. The children were asked to take off their shoes and socks and put them on again and to remove their jacket and put it back on. The environment within which the children were observed was the Occupational Therapy Department or the Paediatric Outpatient Department at TMH. The environment was structured so as to ensure a degree of privacy for the child when performing the

dressing tasks by placing a screen around the child. If the child needed the instructions to be repeated, they were.

3.8 Data analysis

The demographic information as well as all test scores from the SCICP were entered manually into an Excel spreadsheet. The overall domain scores and overall point scores for each participant were represented in an Excel spreadsheet as well as the individual test item scores for each domain of the SCICP. For example, “Eating” items one to nineteen were placed in an Excel spreadsheet and each score from one to four was entered under the test item.

Table 3.1: Data Analysis

Objective	Outcome measure	Analysis
The known-group validity of the test	Ordinal	Mann- Whitney U test was used in order to compare the median score as well as the confidence intervals of the typically developing children to the median score and confidence intervals of the children with CP. This will be done for each age group and for each GMFCS and MACS level.
The internal consistency of the test	Ordinal	Cronbach's alpha test
Scores from the observations and SCICP	Ordinal	Spearman's correlation co-efficient to determine response process
Scores from the GMFCS and the MACS and age and SCICP	Ordinal	Spearman's correlation co-efficient to determine relationship to other measures
Sensitivity and specificity	Ordinal	Sensitivity and specificity statistics Accuracy statistics

The demographic information obtained from the demographic questionnaire was presented in the form of descriptive statistics including frequencies and percentages, which described the characteristics of the data. Methods for organising and representing the data were determined after the raw data were placed in an Excel spreadsheet and analysed using Statistica v 13.2.

All results for the known-group validity, internal consistency and sensitivity and specificity scores were analysed as described in Table 3.1. Due to the ordinal data and the small sample within each age group for the typically developing children and children with CP, non-parametric statistics were used.

3.9 Ethical considerations

Below details how the principles of the Singapore Statement on Research Integrity (Lucas, 2010) was adhered to:

3.9.1 Accountability and honesty in the conduct of research

Ethical clearance for this study was obtained from the University of Witwatersrand's Human Research Ethics Committee (M180954) (Appendix C). Permission from the chief executive officer (CEO), the head of paediatrics and the head of the Occupational Therapy department at TMH were obtained (Appendix D) as well as permission from the CEO of TMRH (Appendix E).

3.9.2 Professional courtesy and fairness in working with others

The research study was explained in detail to all caregivers through the use of a participant information sheet (Appendix F). All documents were made available in English, isiZulu and Sesotho. An information sheet regarding the purpose of the study was provided to the caregivers of the typical, as well as the CP, children. In this information sheet it detailed that there would be no negative consequences to the participants should they decline to take part in the research study or should they withdraw from the research. This was also verbally communicated to caregivers by the researcher or the research assistant. All caregivers were asked to complete an informed consent form (Appendix G) before completing the SCICP. It was also explained to the caregivers that completion of the SCICP provided additional informed consent for their participation in the study. Ten caregivers whose children were recruited to be part of the observation of the dressing tasks during the pilot study were also asked to sign consent for their child to take part in this aspect of the study and for the use of photographs of their children in the research study (Appendix H). Assent was obtained from the children for the observation of the dressing tasks before the assessment took place (Appendix I) and confirmed by their willingness to participate in the activities. This was done in the child's home language by through translation of the caregiver or by the research assistant who could speak all three languages.

3.9.3. Good stewardship of research on behalf of others

Furthermore, caregivers were informed that participation in the study was voluntary and that they could refuse to participate or withdraw their participation at any stage of the research process without any consequence or effect on treatment or therapy received by their child. No identifying information of the children was used during

data capturing or during the data analysis phases of the research process. All children's data was coded with a number on the top corner of each of their forms. The results of the study were available for the caregivers on request. All coded data sheets were kept separate in a secure location by the researcher to ensure confidentiality.

According to the responsibilities as laid out by the Singapore Statement on Research Integrity (Lucas, 2010) the researcher took full responsibility for the trustworthiness of her research by adhering to ethical considerations as stipulated above. Research was conducted according to evidence found in the literature and with the guidance of her research supervisor. Records were kept in numerical order in lever arch files according to the code the researcher gave each research participant in each sample group. These were kept locked away and only the researcher has access to these records. Furthermore, data that was processed electronically was kept in folders on the researcher's laptop. In order to access the computer, a password was needed only known to the researcher. This research acknowledges the contributions of others to the research process. No participants were harmed in any way through their participation in the research study.

3.10 Summary

The study made use of a descriptive, comparative, quantitative, cross-sectional study design. A demographic questionnaire accompanied the SCICP assessment form during data collection. The site of data collection took place at TMH and TMRH. The data was captured and analysed using descriptive statistics, namely the Mann-Whitney U test, Cronbach's alpha and sensitivity and specificity statistics. The researcher and research assistant from TMH also observed five typically developing and five CP children performing certain dressing items, which formed part of the pilot study. The results from these observations were analysed accorded to Spearman's coefficient and p-values to indicate significance.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter will detail the results from the data collection process, which aimed to determine the self-care abilities of children with CP as well as typical children. The contents of this chapter will describe the demographic information of the children in terms of their personal demographics and socio-economic indicators. Thereafter, the results from the SCICP will be analysed according to the study's objectives so as to display aspects of the tool's reliability and validity to identify children with CP and developmental delay.

All children came from households that spoke either isiZulu or Sesotho as their home language. The SCICP was initially formulated for a rural South African population from a resource-constrained and low socio-economic background. This convenient sample of children with CP and typical children were accessed at TMH in Boksburg and children with CP were also accessed at TMRH in Vosloorus. The scores of the SCICP were compared between the 54 children with CP and the 51 typical participants. The age bands of the CP children ranged from one to eight-years-old and the age bands of the typical children ranged from nought to six-years-old. Not all caregivers completed all information on the demographic questionnaire. The number of missing answers is indicated in each section in the results.

4.2 Demographic information

4.2.1 Personal demographics of the children

Figure 4.1 indicates that the sample consisted of a total of 56 males and 49 female participants. In total, there were 54 children with CP (55% male and 45% female) and a total of 51 typically developing participants (51% male and 49% female).

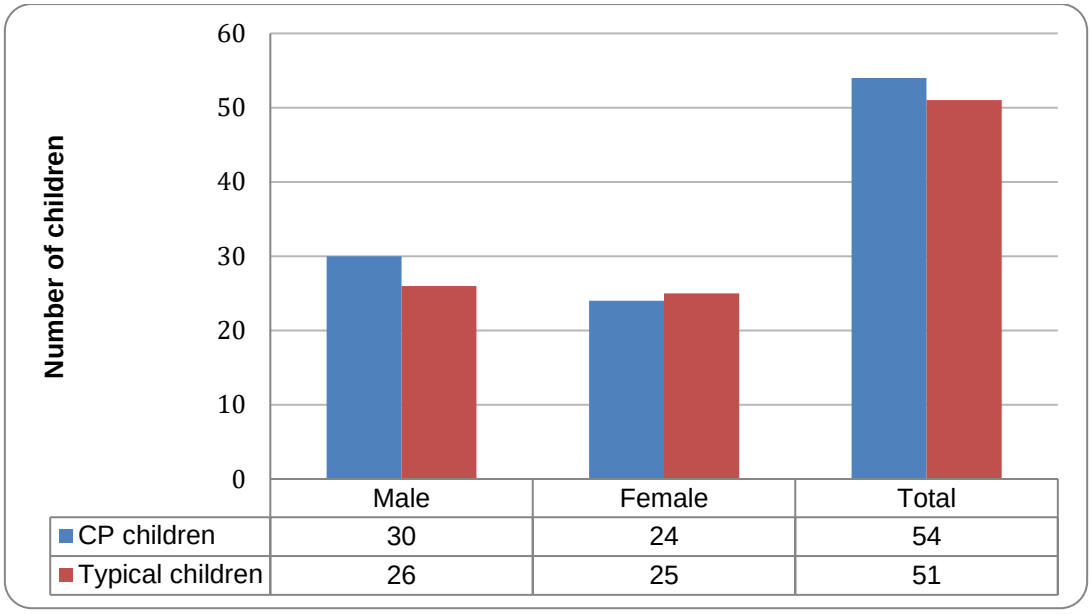


Figure 4.1: Gender distribution of children with cerebral palsy and typical children

The ages of the children in the sample groups varied between nought to eight-years-old. The largest number of children with CP was aged between one to five-years-old (78%) (Table 4.1).

Table 4.1: Ages of children with cerebral palsy and typical children

Age (in years)	Children with cerebral palsy	Typical children
	n (%)	
0	0 (0)	9 (17,6)
1	7 (13)	12 (23,5)
2	10 (18,5)	9 (17,6)
3	10 (18,5)	9 (17,6)
4	7 (13)	3 (5,9)
5	9 (16,7)	6 (11,8)
6	5 (9,3)	3 (5,9)
7	3 (5,6)	0 (0)
8	2 (3,7)	0 (0)
Missing	1 (1,9)	0 (0)
Total	54 (100)	51 (100)

The typical children were predominantly between the ages of nought to five-years-old (94%). The number of typical children aged four (n=3; 6%) and six (n=3; 6%) years old in the sample was less than in the other age groups. For the CP children, the number of children aged six (n=5; 9%), seven (n=3; 6%) and eight (n=2; 4%) years old were much less than the amount of children in the other age groups.

4.2.2 Birth history of children with cerebral palsy and typical children

4.2.2.1 Birth mode

Table 4.2 describes the mode of birth delivery for the two sample groups. Thirty-three of the total 54 CP children were born via normal vaginal delivery (NVD), 13 (24%) were delivered via Caesarean section and eight (15%) participants failed to answer the question. Of the 51 typical participants, 39 (76%) were born via NVD, 11 (22%) via Caesarean section and only one caregiver failed to produce this information.

Table 4.2: Birth mode of children with cerebral palsy and typical children

Category	Children with cerebral palsy	Typical children
	n (%)	
Natural vaginal delivery	33 (61,1)	39 (76,5)
Caesarean Section	13 (24,1)	11 (21,6)
Missing	8 (14,8)	1 (2)
Total	54 (100)	51 (100)

4.2.2.2 Gestational period of children with cerebral palsy and typical children in weeks

Information regarding the gestational period for the population sample was obtained. The gestational periods were classified into early prematurity (less than 34 weeks), late prematurity (34-37 weeks), full term (38-40 weeks) and more than full term (any amount of time post 40 weeks). Below is a table representative of the gestational period among the children with CP and typical children.

In the majority of both samples, children were born at full term. Eight (15%) children with CP and five (10%) typical children were classified as early prematurity and seven (13%) CP and six (12%) typical children were classified as late prematurity babies (Quinn *et al.*, 2016). One (2%) child with CP and three (6%) typical children were born after 40 weeks. Nine (17%) CP children and four (8%) typical children's gestational period information was missing from the sample (Table 4.3).

Table 4.3: Gestational period of children with cerebral palsy and typical children in weeks

Category	Children with cerebral palsy	Typical children
	n (%)	
Less than 34 weeks	8 (14,8)	5 (9.8)
Between 34-37 weeks	7 (13)	6 (11,8)
38-40 weeks	29 (53,7)	33 (64,7)
More than 40 weeks	1 (1,9)	3 (5,9)
Missing	9 (16,7)	4 (7,8)
Total	54 (100)	51 (100)

4.2.2.3 Birth complications

Regarding the birth complications, only 14 (26%) of the children with CP did not have any birth complications, whereas 40 (78%) of the typical children did not experience any complications at birth. Caregivers of 15 (27%) children with CP did not specify whether there were any birth complications present and only one (2%) of the caregivers of a typical child did not produce any information regarding this detail. In general, birth asphyxia (n=7; 13%) and neonatal encephalopathy (NNE) (n=6; 11%) were the most common birth complications in the children with CP. Two participants (4%) had meningitis and one parent commented on the fact that the child was born with hydrocephalus (2%). Prolonged labour (n=2; 4%) and foetal distress (n=1; 2%) were among the other complications in the sample of CP children. In the sample of typical children, two of the children had NNE (4%) at birth, two (4%) presented with asphyxia; two (4%) with neonatal jaundice (NNJ) and one (2%) child had pneumonia shortly after birth.

Table 4.4: Birth complications of children with cerebral palsy and typical children

Category	Children with cerebral palsy	Typical children
	n (%)	
Neonatal Encephalopathy	6 (10,9)	2 (3,9)
Meningitis	2 (3,6)	0 (0)
Asphyxia	7 (12,7)	2 (3,9)
Hydrocephalus	1 (1,8)	0 (0)
Prolonged labour	2 (3,6)	0 (0)
Foetal distress	1 (1,8)	0 (0)
Neonatal Jaundice	2 (3,6)	2 (3,9)
General	5 (9,1)	3 (5,9)
None	14 (25,5)	40 (78,4)
Pneumonia	0 (0)	1 (2,0)
Missing	15 (27,3)	1 (2,0)
Total birth complications	55 (100)	51 (100)
*Some children presented with more than one complication		

The aforementioned medical terms of the birth complications experienced by the caregivers of the CP children were either extrapolated by the researcher or if the hospital file was available, the researcher was able to ascertain the information from the file. Caregivers wrote a description to the question on the demographic questionnaire, “Any illnesses or birth complications?” such as “the child had difficulty breathing” or “lack of oxygen” (birth asphyxia), “jaundice” (NNJ), “fits” (seizures or NNE), “long labour” (prolonged labour). The two caregivers whose children had meningitis were able to state the name of the condition as well as the caregiver whose child has hydrocephalus. General birth complications were obtained from responses such as, “baby stayed in ICU (intensive care unit) for two months” or “baby was in the neonatal ICU” or answering “yes”.

4.2.3 Medical history – children with cerebral palsy

The children with CP had additional demographic variables that were important to note due to the nature of their medical condition and how these variables might affect their ability to perform their self-care tasks. Variables such as the GMFCS as well as the participants' MACS levels were recorded. Additional information was gathered to determine whether the sample of children with CP had a hearing or visual impairment. Furthermore, information was obtained as to whether they suffered from epilepsy or not and whether the children ate orally or via a percutaneous endoscopic gastrostomy (PEG). Lastly, information regarding the types of CP were also recorded.

4.2.3.1 Types of cerebral palsy

The children with CP were classified according to different types of CP. The most common type of CP among the sample was spastic quadriplegia (n=19; 35%) and spastic quadriplegia with elements of dystonia (n=12; 22%). Two children presented with hydrocephalus (4%) in addition to their classification of spastic quadriplegia.

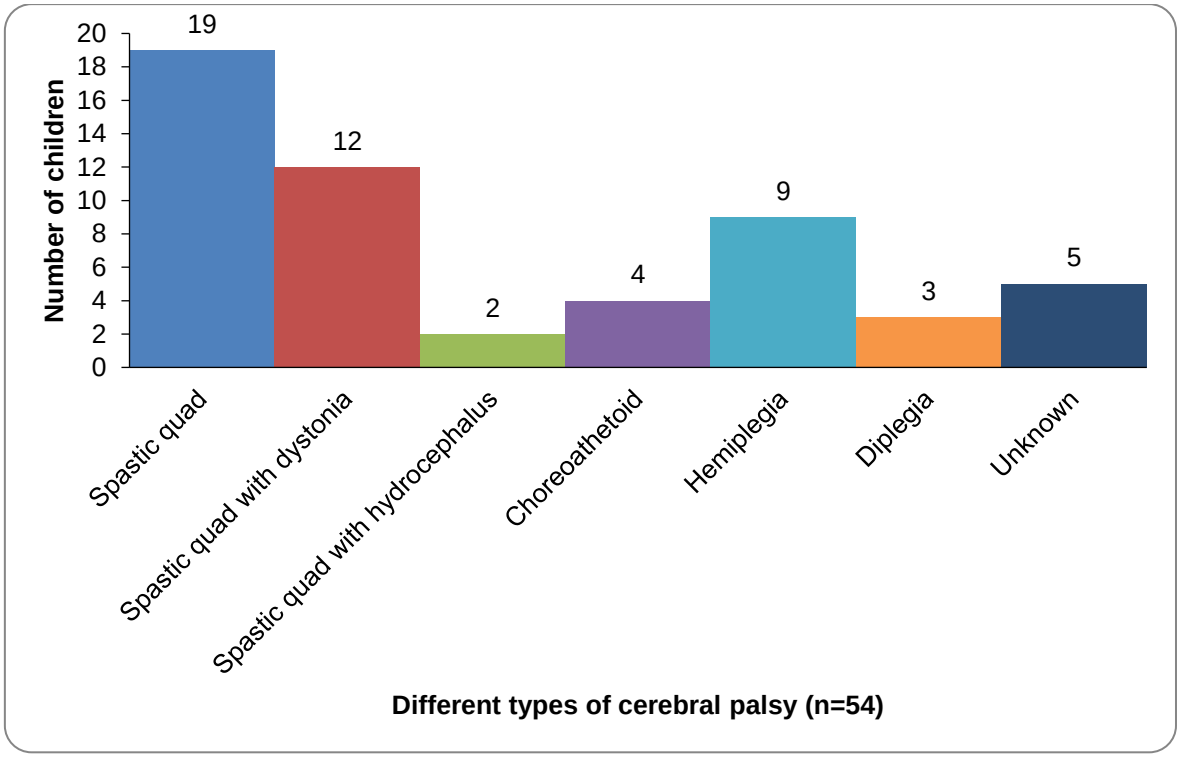


Figure 4.2: Types of cerebral palsy

There were four children with dyskinetic, choreoathetoid type CP (7%), nine children with hemiplegia (17%) and three children with diplegia (6%).

4.2.3.2 Classification scale levels for children with cerebral palsy

According to the GMFCS and MACS levels, the children with CP fell into the following categories:

Table 4.5: Gross Motor Function Classification System (GMFCS) level and Manual Abilities Classification System (MACS) level for children with cerebral palsy

	GMFCS level	MACS level
Level	n (%)	
I	4 (7,4)	3 (5,6)
II	5 (9,3)	4 (7,4)
III	3 (5,6)	10 (18,5)
IV	18 (33,3)	8 (14,8)
V	18 (33,3)	22 (40,7)
Missing	6 (11,1)	7 (13)
Total	54 (100)	54 (100)

Two thirds of the children with CP were classified on GMFCS level IV (n=18; 33%) and level V (n=18; 33%) indicating severe limitations in mobility, being wheelchair or buggy bound and unable to move by him or herself. More than half of this sample also presented with MACS level IV (n=8; 15%) and level V (n=22; 41%) indicating severe difficulty with hand function and handling objects.

4.2.3.3 Hearing and visual impairment

In terms of visual and hearing impairment, the responses from the caregivers showed that four (7%) children with CP had been diagnosed with hearing impairment, 38 (70%) did not have any problems with their hearing, three (6%) were unsure if there was a problem with their child's hearing and nine (17%) participants did not answer the question. Visual impairment, predominantly cerebral visual impairment (CVI) affected a greater portion of the sample of children with CP.

Nineteen (35%) of these children had confirmed visual impairment, five (9%) did not have any vision problems, 23 (43%) caregivers were unsure if their child had a problem with their sight and seven (13%) caregivers did not complete the information on the demographic questionnaire.

Table 4.6: Hearing and visual impairment children with cerebral palsy

Hearing impairment		**Visual impairment**	
Category	**Count**	**Category**	**Count**
	n (%)		n (%)
Yes	4 (7,4)	Yes	19 (35,2)
No	38 (70,4)	No	5 (9,3)
Unsure	3 (5,6)	Unsure	23 (42,6)
Missing	9 (16,7)	Missing	7 (13)
Total	54 (100)	Total	54 (100)

4.2.3.4 Feeding impairment

Caregivers were asked how their children ate, whether it was orally or through a PEG. Of the 54 CP children, 43 (80%) ate orally and four (7%) required PEG feeding indicating severe difficulties with eating and drinking. Seven (13%) caregivers failed to record the information on the questionnaire. The four children who required PEG feeding scored a one, indicating complete dependence in all test items of eating (19 items) and functional mobility associated with eating (10 items). These children only achieve the lowest possible score for each domain, namely, 19 and 10. This would indicate a greater severity of disability, a greater burden of care on caregivers and a lack of typical performance with regards to feeding.

4.2.3.5 Epilepsy

Caregivers were also asked if their children had epilepsy or not. Of the 54 children in the sample, 24 (44%) children had a confirmed diagnosis of epilepsy, 29 (54%) did not have epilepsy and one (2%) child's information regarding this detail was not recorded.

4.2.4 Socio-economic indicators

4.2.4.1 Caregiver and household employment

All participants came from a resource-constrained and low socio-economic background. The number of caregivers of children with CP who were employed accounted for less than half of the total sample, 25 (46%) caregivers. In the typical group only 15 (29%) of caregivers were employed. However, in some households, there were other members of the household who were employed. In the sample of children with CP, 18 (33%) of the households had no people employed and in the typical population, 19 (37%) households had no source of income from employment (Figure 4.3).

Table 4.7: Levels of employment of caregivers of children with cerebral palsy and typical children

Category	Caregivers of children with cerebral palsy	Caregivers of typical children
	n (%)	
Employed	25 (46,3)	15 (29,4)
Unemployed	26 (48,1)	35 (68,6)
Missing	3 (5,6)	1 (2)
Total	54 (100)	51 (100)

Sixteen households (30%) in the sample of children with CP had at least one person that was employed and in the typical population, 10 (19%) households had one person living with them that was employed.

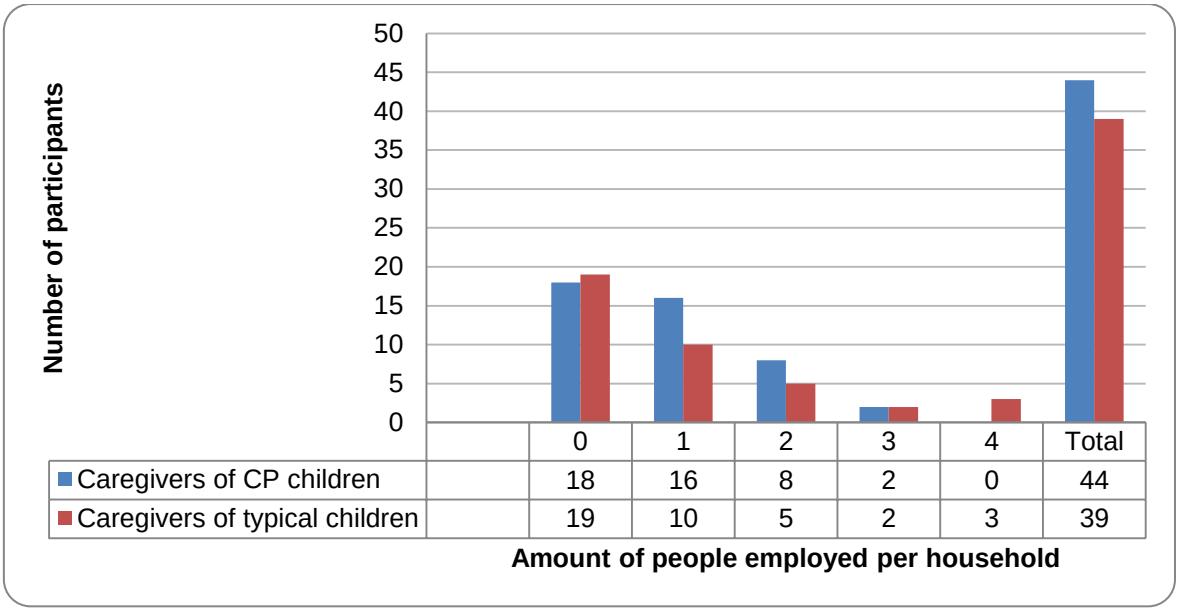


Figure 4.3: Employment rates per household for children with cerebral palsy and typical children

Other households, as seen in Figure 4.3 had between two to four people employed. The general types of employment for the children with CP and typical children samples included jobs such as; retail, domestic worker, construction worker, nurse, teacher, driver, cleaner, carer in a home, sales consultant, receptionist and piece jobs.

4.2.4.2 Social grants

The majority of the caregivers of the children with CP and typical population earned a source of income from social grants for their children. Of the 54 children with CP, 42 (78%) received a social grant. The types of social grants varied among the children with CP; two (4%) children received child support grants, 34 (63%) received the care dependency grant and the remaining six (11%) did not specify what type of grant they received. Twelve (22%) children with CP received no grant at all. Among the typical population, 32 (63%) children received child support grants and five (10%) did not specify what type of grant they received. Fourteen (27%) of these children did not receive any grant (GroundUp, 2012).

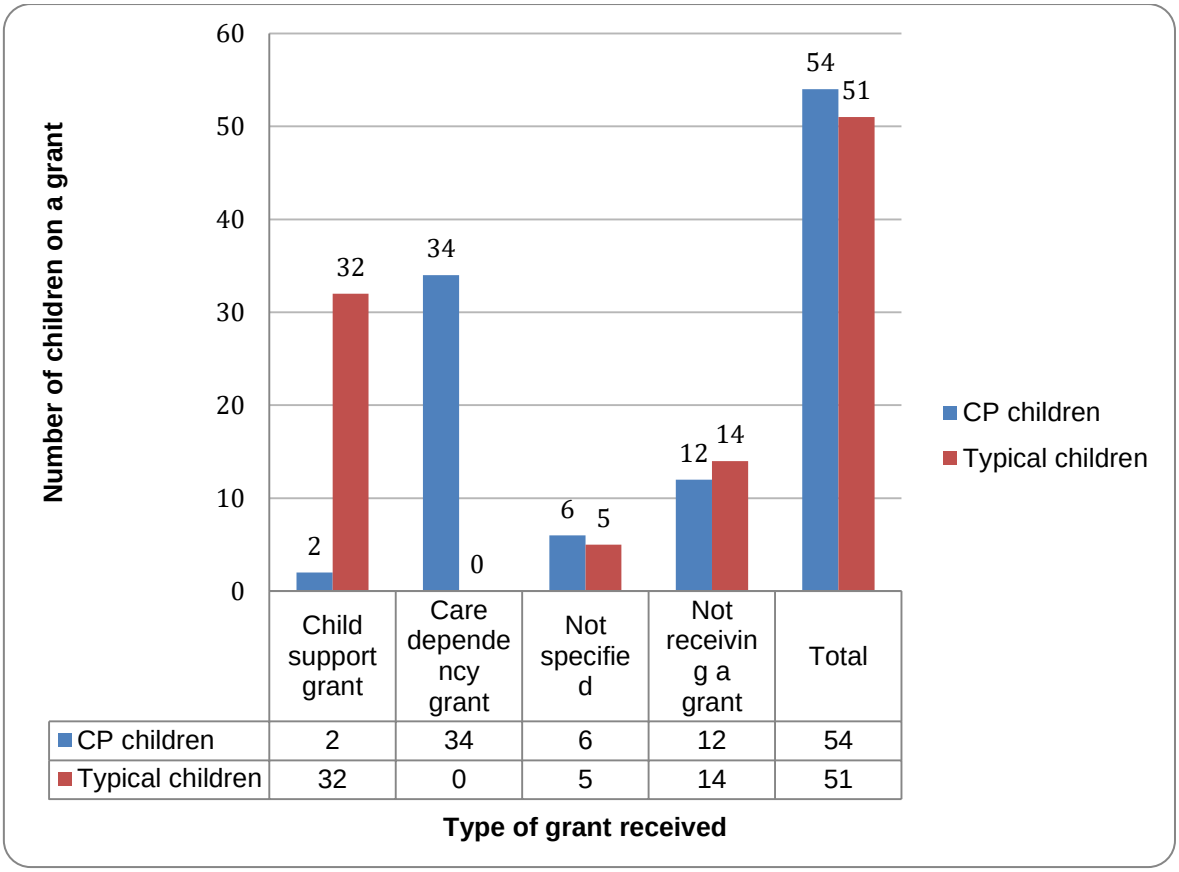


Figure 4.4: Social grants received for children with cerebral palsy and typical children

4.2.4.3 Household amenities

Water and electricity status varied among participants, the majority of participants had access to water and electricity.

Table 4.8: Access to water and electricity in households for children with cerebral palsy and typical children

Category	Households of children with cerebral palsy	Households of typical children
	n (%)	
Yes	47 (87)	46 (90,2)
No	5 (9,3)	3 (5,9)
Missing	2 (3,7)	2 (3,9)
Total	54 (100)	51 (100)

Forty-seven (87%) out of the 54 households with children with CP stated that they had access to both facilities, five (9%) did not and two (4%) of the participants' information was missing. Of the 51 typical children, 46 (90%) of their households had access to running water and electricity and three (6%) did not. Two (4%) typical participants' information was missing. According to where caregivers stated that they lived, it was noted that 50 (93%) CP children lived in informal settlements in the Ekurhuleni district. Data was missing from four (7%) of the CP children whose caregivers did not write down an address. It was noted that 47 (92%) of caregivers and typical children lived in informal settlements. Data was missing for four (8%) of the typical children.

4.3 Self-Care Inventory for Children with Cerebral Palsy

4.3.1 Objective 1: To determine the known-group validity of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay.

4.3.1.1 Typical children

Table 4.9 displays the median and 95% confidence interval scores for each domain on the SCICP for each age group of the typical sample. For the typical children, one can see that for each domain, the scores of the children increases steadily as the child increases in age. In the case of the four-year-old group, the difference is not as great when compared to the three-year-olds as it is between the other age groups. However, there was still a difference in the overall score between the three and four-year-olds. The overall median scores for the different age groups were as follows; the nought-year-old group received an overall median score of 149, the one-year-olds scored 232 overall, the two-year-olds received 298, the three-year-olds scored 393, the four-year-olds scored 399, the five-year-olds scored 410,5 and the six-year-olds scored an overall score of 435. The typical children's scores for each age group will serve as a comparison of normal development against the CP children's scores.

Table 4.9: Typical children within group scores

	0 years (n=9)		1 year (n=12)		2 years (n=9)		3 years (n=9)		4 years (n=3)		5 years (n=6)		6 years (n=3)	
	Median and 95% CI													
Eating	37	28,19 - 51,15	54	42,99 - 57,51	64	58,05 - 67,28	67	63,57 - 72,21	70	54,21 - 82,46	68	63,56 - 75,11	76	74,23 - 77,10
FM Eating	11	9,21 - 20,79	23,5	16,86 - 28,64	33	26,02 - 35,31	35	33,13 - 37,54	37	27,94 - 45,39	39	37,44 - 40,23	40	N/A
Dressing	23	22,65 - 24,68	31	28,64 - 36,86	53	48,81 - 72,97	84	67,65 - 87,24	82	62,74 - 102,59	92	84,27 - 94,06	92	90,23 - 93,10
FM Dressing	2	N/A	2	N/A	2	1,71 - 3,85	6	4,13 - 7,20	6	3,80 - 9,54	7,5	6,48 - 8,19	8	N/A
Washing	10	9,77 - 11,12	16	12,40 - 18,27	24	17,68 - 29,66	31	28,31 - 34,80	34	21,58 - 46,42	36,5	34,74 - 39,60	40	N/A
FM Washing	11	8,52 - 19,70	22,5	18,04 - 24,96	26	23,07 - 26,71	26	25,30 - 29,37	30	22,93 - 34,40	31,5	29,67 - 32,33	32	N/A
Toileting	5	N/A	5	4,89 - 6,61	11	7,83 - 12,17	19	16,21 - 20,01	18	13,03 - 22,97	20	19,12 - 20,21	20	N/A
FM Toileting	9	8,85 - 11,15	14,5	11,41 - 17,59	24	20,74 - 27,26	34	30,92 - 35,97	34	29,03 - 38,97	36	34,62 - 36,38	36	N/A
Grooming	12	9,99 - 20,01	17,5	15,62 - 23,05	25	19,64 - 30,58	32	28,31 - 34,36	33	22,29 - 42,37	32	29,70 - 35,30	36	34,23 - 37,10
FM Grooming	2	1,85 - 2,37	4	2,69 - 4,98	7	5,42 - 7,47	8	6,67 - 8,22	8	6,23 - 9,10	8	N/A	8	N/A
FM Sleeping	5	3,34 - 7,77	10	7,35 - 11,15	12	11,44 - 12,12	12	N/A	12	N/A	12	N/A	12	N/A
General mobility	24	14,44 - 28,23	31	23,41 - 32,92	35	33,77 - 36,01	36	34,06 - 36,16	36	32,46 - 38,20	35	34,38 - 35,96	36	N/A
Overall score	149	130,99 - 196,79	232	194,46 - 256,54	298	290,50 - 349,05	393	355,02 - 410,31	399	311,68 - 480,99	410,5	398,44 - 432,89	435	432,52 - 437,48

4.3.1.2 Children with cerebral palsy

Table 4.10 displays the medians and 95% confidence interval scores for the children with CP. The scores show that for every domain for each age group, the scores are lower than that of the typical sample of children. As the children with CP increase in age, the difference in scores becomes greater between the children with CP and the typical children. The median scores for each domain for the CP children remain relatively stable over time, except for the seven and eight-year-old children whose scores were greater than the one to six-year-olds. The CP children between the ages of one to six-years-old had variations in their overall median and 95% confidence interval scores. According to the CP children, age did not necessarily indicate that their scores increased. The six-year-old sample, for example, had an overall median score of 136, whereas, the four and five-year-olds had an overall median score of 155. The three-year-old group scored higher than the six-year-old group with 139. The two-year-olds overall median score was 122, 5 whilst the one-year-olds overall score was 133.

Table 4.10: Children with cerebral palsy within group scores

	1 year (n=7)		2 years (n=10)		3 years (n=10)		4 years (n=7)		5 years (n=9)		6 years (n=5)		7 years (n=3)		8 years (n=2)	
	Median and 95% CI															
Eating	31	22,38 - 49,34	28,5	22,56 - 46,64	39,5	28,98 - 52,82	33	24,66 - 57,63	38	31,75 - 61,14	33	22,00 - 40,00	65	24,22 - 93,78	45,5	1,37 - 77,27
FM Eating	11	7,62 - 23,81	10	8,46 - 21,74	10	8,71 - 20,69	13	8,07 - 21,64	14	12,11 - 29,23	10	9,29 - 11,51	34	1,30 - 56,03	23	1,03 - 35,71
Dressing	23	16,89 - 42,54	23	22,17 - 31,63	23	19,97 - 37,43	24	20,84 - 49,44	24	21,15 - 55,07	23	19,44 - 29,76	60	29,71 - 82,29	41	0,00 - 269,71
FM Dressing	2	1,17 - 3,97	2	N/A	2	1,73 - 3,27	2	1,59 - 2,98	2	1,58 - 3,75	2	N/A	4	2,90 - 5,77	4	0,00 - 29,41
Washing	10	6,86 - 20,57	10	8,61 - 19,19	10	7,68 - 21,52	11	8,61 - 21,39	14	10,44 - 26,67	10	9,29 - 11,51	33	10,02 - 47,31	26,5	0,74 - 45,56
FM Washing	10	7,21 - 17,08	10	8,41 - 18,19	10,5	8,75 - 19,05	14	9,91 - 23,24	15	10,44 - 24,01	11	7,83 - 14,17	19	2,28 - 41,72	17,5	0,00 - 100,09
Toileting	5	3,35 - 8,94	5	3,86 - 7,94	5	3,57 - 9,83	5	3,52 - 15,05	6	4,68 - 11,76	5	4,64 - 5,76	10	0,00 - 27,68	12	N/A
FM Toileting	11	9,24 - 13,33	9,5	8,68 - 15,32	10	7,78 - 18,42	15	8,98 - 26,73	12	9,70 - 26,08	11	8,58 - 13,02	19	4,70 - 40,64	19,5	0,00 - 127,50
Grooming	10	8,58 - 15,42	12	9,21 - 20,59	12,5	9,52 - 20,48	18	12,74 - 26,41	14	12,82 - 28,52	14	10,23 - 18,57	29	7,37 - 45,96	26	0,00 - 89,53
FM Grooming	2	1,59 - 2,98	2	1,86 - 3,94	2	1,86 - 4,34	3	1,98 - 5,16	3	2,52 - 6,37	2	1,44 - 4,16	6	1,87 - 9,46	4	0,00 - 29,41
FM Sleeping	3	1,46 - 7,68	3	2,94 - 8,46	3	2,83 - 7,37	3	2,04 - 9,11	5	4,43 - 10,68	3	2,49 - 4,71	12	1,39 - 18,61	9	0,00 - 21,71
General mobility	11	6,02 - 22,84	9	8,00 - 23,80	9,5	8,30 - 20,90	14	8,67 - 26,76	11	9,60 - 26,84	9	6,02 - 16,78	28	5,78 - 48,22	26,5	0,00 - 58,27
Overall score	133	106,98 - 213,88	122,5	107,29 - 216,91	139	112,52 - 233,28	155	123,70 - 273,44	155	135,76 - 305,57	136	120,74 - 154,46	325	108,67 - 499,33	254,5	0,00 - 553,10

4.3.2 Between group scores

The scores for the typical children and the children with CP were compared for each age group. Children with CP in the seven and eight-year-old age groups were also compared to the typical six-year-old children. Figure 4.5 and Table 4.11 depict the difference in overall median point scores and the overall confidence interval scores for the children with CP and typical children on the SCICP.

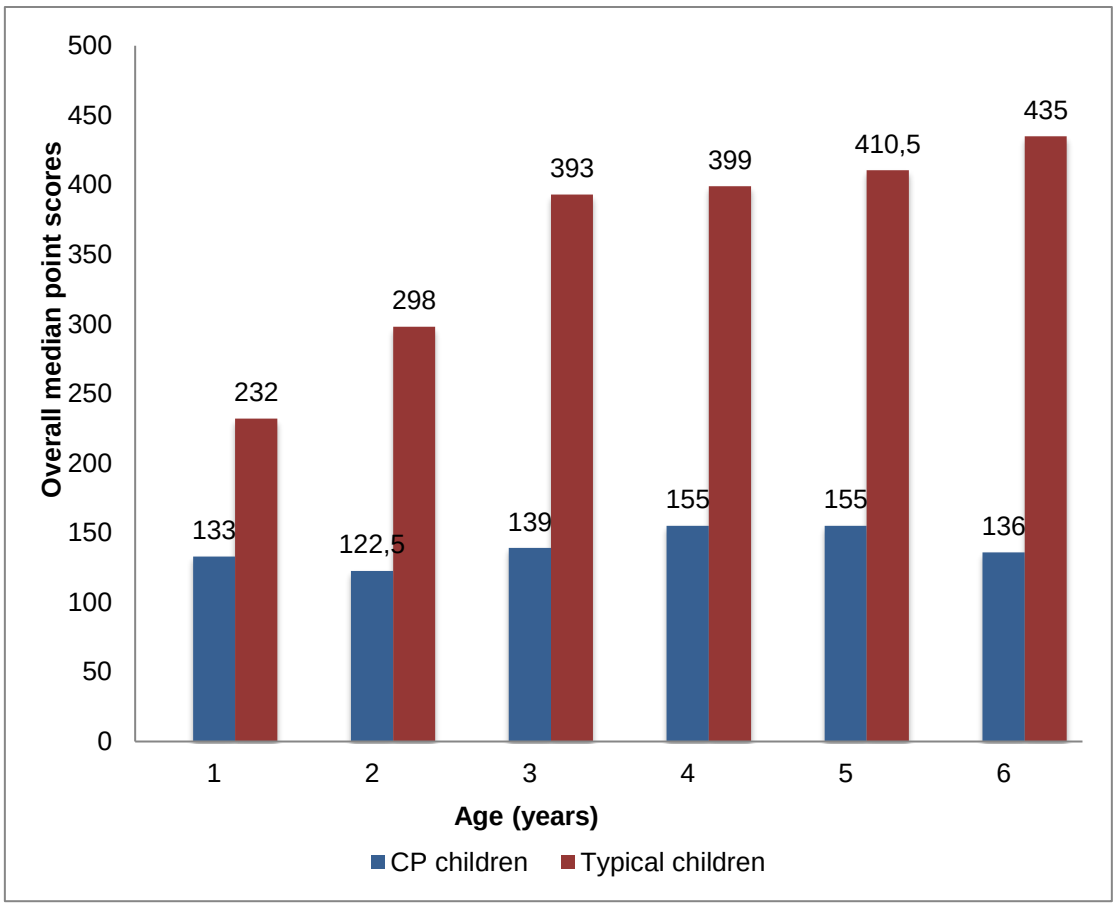


Figure 4.5: Overall median point scores comparing children with cerebral palsy and typical children ages one to six-years-old

The typically developing children's overall median point and overall 95% confidence interval scores on the SCICP increased steadily as their chronological age increased. The children with CP's scores remain relatively consistent over time, as the CP children increased in age; there is little change in the SCICP scores.

Table 4.11: Confidence interval range for overall point scores

Age	Children with cerebral palsy		Typical Children	
	Overall median point score	Overall confidence interval score	Overall median point score	Overall confidence interval score
1	133	106,98 – 213,88	232	194,46 – 256,54
2	122,5	107,29 – 216,91	298	290,50 – 349,05
3	139	112,52 – 233,28	393	355,02 – 410,31
4	155	123,70 – 273,44	399	311,68 – 480,99
5	155	135,76 – 305,57	410,5	398,44 – 432,89
6	136	120,74 – 154,46	435	432,52 – 437,48

4.3.2.1 Differences between the typical children and children with cerebral palsy scores according to age

The Mann-Whitney U test, a non-parametric test, was used in order to determine if there was a significant difference between two sample groups, thereby confirming known-group validity of the research tool (Bryman, 2012). A statistically significant difference was found between the two groups for the majority of the scores across all of the domains and age groups. When comparing the scores for the one-year-old groups of typical children and children with CP, the majority of the test domains were not statistically significantly different. It is interesting to note, however, that the overall point score for this age group still showed a significant difference (p=0,04). Other areas for this age group that showed statistical significance were found in the domains of general mobility (p=0,02), functional mobility associated with sleeping (p=0,02), grooming (p=0,01) and functional mobility associated with washing (p= 0,01). With regards to the two-year-old age groups there was no significant difference for dressing while in the four-year-old age groups; the statistical difference between the groups was not that significant for toileting (p=0,11). All other test domains for each age group were statistically significant when comparing the scores of the children with CP to the typically developing children (Table 4.12).

Table 4.12: Significant differences in test scores by age

	1 year			2 years			3 years			4 years			5 years			6 years		
	CP (n=7)	T (n=12)	p-val	CP (n=10)	T (n=9)	p-val	CP n=10)	T (n=9)	p-val	CP (n=7)	T (n=3)	p-val	CP (n=9)	T (n=6)	p-val	CP (n=5)	T (n=3)	p-val
Eating	31	54	0.06	28.5	64	***0.00**	39.5	67	***0.00**	33	70	**0.02**	38	68	***0.03**	33	76	***0.01**
FM Eating	11	23,5	0.16	10	33	***0.00**	10	35	***0.00**	13	37	***0.02**	14	39	***0.01**	10	40	***0.01**
Dressing	23	31	0.09	23	53	***0.00**	23	84	***0.00**	24	82	***0.02**	24	92	***0.00**	23	92	***0.01**
FM Dressing	2	2	0.64	2	2	0.24	2	6	***0.00**	2	6	***0.02**	2	7,5	***0.00**	2	8	***0.01**
Washing	10	16	0.27	10	24	***0.02**	10	31	***0.00**	11	34	***0.02**	14	36,5	***0.00**	10	40	***0.01**
FM Washing	10	22,5	***0.01**	10	26	***0.00**	10.5	26	***0.00**	14	30	***0.04**	15	31,5	***0.00**	11	32	***0.01**
Toileting	5	5	0.64	5	11	***0.00**	5	19	***0.00**	5	18	0.11	6	20	***0.00**	5	20	***0.03**
FM Toileting	11	14,5	0.20	9.5	24	***0.00**	10	34	***0.00**	15	34	***0.04**	12	36	***0.01**	11	36	***0.01**
Grooming	10	17,5	***0.01**	12	25	***0.03**	12.5	32	***0.00**	18	33	***0.05**	14	32	***0.03**	14	36	***0.01**
FM Grooming	2	4	0.08	2	7	***0.00**	2	8	***0.00**	3	8	***0.03**	3	8	***0.02**	2	8	***0.01**
FM Sleeping	3	10	***0.02**	3	12	***0.01**	3	12	***0.00**	3	12	***0.05**	5	12	***0.04**	3	12	**0.05**
General mobility	11	31	***0.02**	9	35	***0.00**	9.5	36	***0.00**	14	36	***0.04**	11	35	***0.01**	9	36	***0.01**
Overall score	133	232	***0.04**	122.5	298	***0.00**	139	393	***0.00**	155	399	***0.02**	155	410,5	***0.00**	136	435	***0.01**

CP=Children with CP median score

T=Typical children median score

p-val=p-value from Mann-Whitney U Test (w/ continuity correction)

Significant difference p ≤ 0.05*

4.3.3 Objective 2: To determine the content validity (response process and relationship to other measures) of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay.

4.3.3.1 Correlation of Self-Care Inventory for Children with Cerebral Palsy and observations of self-care tasks

To further test the response process of the SCICP scores that were obtained while observing children perform a selection of self-care tasks were correlated with the scores provided by the caregivers of the children.

The researcher observed five typical and five CP children performing a number of dressing activities that displayed functional mobility as well as gross and fine motor components to determine whether caregiver scores correlated with the researcher and research assistant's scores. Spearman's coefficient of rank correlation (rho) was used to determine the strength and direction of correlation between the variables. For the typical group of children that were observed, the caregivers overall score was 28 while that of the researcher was 27 with a strong correlation (r=0,69). For the children with CP, the caregivers overall score was 51 while that of the researcher was 45, with a moderate correlation between the scores at r=0,48. Both these correlations were significant.

4.3.3.2 Relationship between the Self-Care Inventory for Children with Cerebral Palsy and age group, Gross Motor Function Classification System (GMFCS) level and Manual Abilities Classification System (MACS) level

To determine the relationship between the variables in this study the scores of the SCICP were correlated with the age group and functional classification levels (the GMFCS and MACS) for the children with CP.

Table 4.13 indicates that when the relationship between the SCICP scores for children with CP and their GMFCS and MACS levels were compared, a negative correlation was observed. As the GMFCS and MACS level increases (higher levels indicate greater restrictions in gross motor and hand function ability), the children's scores decreased. A strong to moderate correlation was observed when comparing the scores of children with CP with their GMFCS levels (r=0,46 to -0,78). All

correlations were statistically significant. Although the CP children's MACS level scores were also significantly correlated, these correlations were weak to moderate (r=-0,36 to -0,65). The age of the children with CP had the weakest correlation with their SCICP scores for each of the 12 test domains and ranged from r=-0,28 to -0,44.

Table 4.13: Age, Gross Motor Function Classification System (GMFCS) level and Manual Abilities Classification System (MACS) level correlations for children with cerebral palsy

	Age (years)	GMFCS level	MACS level
Eating	0,28*	-0,69*	-0,49*
FM Eating	0,24	-0,71*	-0,65*
Dressing	0,23	-0,62*	-0,51*
FM Dressing	0,28*	-0,46*	-0,36*
Washing	0,27	-0,68*	-0,55*
FM Washing	0,26	-0,72*	-0,52*
Toileting	0,39*	-0,57*	-0,45*
FM Toileting	0,27	-0,65*	-0,51*
Grooming	0,44*	-0,65*	-0,50*
FM Grooming	0,37*	-0,78*	-0,46*
FM Sleeping	0,28*	-0,78*	-0,57*
General mobility	0,2	-0,73*	-0,64*
Overall score	0,35*	-0,73*	-0,56*
Significant at $p < 0,05$*			

The correlations using Spearman's rho denotes that the age of the children with CP was not as strongly correlated with their ability to complete their self-care tasks as it was to the children's GMFCS and MACS levels (Table 4.13). This indicated that gross motor functioning, and to a lesser extent, hand function, were greater indicators of independence in self-care tasks than age.

4.3.4 Objective 3: To determine the diagnostic accuracy in terms of sensitivity, specificity of the SCICP for children with CP and typically developing children aged one to six years

Sensitivity and specificity are measures of known-group validity. They can be used to determine the ability of the SCICP to correctly identify children with deficits (true positive rate), or correctly identify children without deficits (true negative rate) (Deeks and Altman, 2004). Sensitivity and specificity of a test can be combined to provide likelihood ratios or how many more, or less, times children with CP are likely to present with a deficit in self-care than typical children. A positive likelihood ratio greater than one indicates that the SCICP can identify definite deficits in children with CP and that the child will require intervention. A negative likelihood ratio of below one indicates an absence of deficits in typical children. Therefore, they will not be identified as requiring intervention (Deeks and Altman, 2004; Akobeng, 2007). These ratios enhance the usefulness of diagnostic, or screening tests (Akobeng, 2007).

Table 4.14: Sensitivity and specificity of the Self-Care Inventory for Children with Cerebral Palsy

SCICP (n=105)		Sensitivity %	Specificity %	Positive Likelihood Ratio	Negative Likelihood Ratio	Accuracy
		%				%
Overall		87,5	74,4	3,4	0,2	80,9
	95 % CI	74,1-94,8	58,5-85,9	2,0-5,8	0,1-0,4	71,3-88,4
1-year-olds		71,4	66,7	2,1	0,4	69.1
	95 % CI	30,2-94,8	35,4-88,7	0,8-5,4	0,1-1,5	44,0-87.5
2-year-olds		90	66,7	2,7	0,15	78,3
	95 % CI	54,1-99,4	30,9-90,9	1,0-6,9	0,0-1,1	53,7 -93,6
3-year-olds		90	77,8	4,1	0,1	83,9
	95 % CI	54,1-99,4	40,1-96,1	1,2-13,9	0,0-0,9	60,0 - 96,4
4-year-olds		85,7	100	Infinity	0,1	92,8
	95 % CI	42,0-99,2	30,9-100		0,0-0,9	59,0 - 99,9
5-year-olds		88,9	71,4	3,1	0,2	80,2
	95 % CI	50,7-99,4	30,2-94,9	0,9-10,3	0,0-1,1	53,1- 95,4-
6-year-olds		100	100	Infinity	0	100
	95 % CI	46,3-100	30,9-100			63,1- 100,0

The overall score of the children with CP shows that when compared to the lower band of the 95% confidence interval of the overall score of the typical children, the SCICP had 87,5% sensitivity and 74,4% specificity. The positive likelihood ratio for the overall score was 3,4 and the negative likelihood ratio was 0,2. The SCICP is 80,9% accurate in identifying self-care deficits in children with CP.

The sensitivity and specificity of the SCICP increases as the children's age increases and as typical children become more independent in self-care. At two and

three years of age, the SCICP is 90% sensitive in identifying children with CP and 66,7% and 77,8% specific for not identifying children with CP. The positive likelihood ratio of the SCICP at two-years-old is 2,7 and the negative likelihood ratio of the SCICP for this age group is 0,15. This increases to a positive likelihood ratio of 4,1 for the three-year-old group with a negative likelihood of 0,1. The four-year-old group displayed 85,7% sensitivity and 100% specificity. The likelihood ratios were infinity for the positive ratio and 0,1 for the negative ratio. In the five-year-old group, the sensitivity of the test was at 88,9% and lower than the four-year-old group for specificity with 71,4%. The positive likelihood ratio was 3,1 and 0,2 for the negative likelihood ratio. The six-year-old group showed 100% sensitivity and specificity on the SCICP and displayed a positive likelihood ratio of infinity and a negative likelihood ratio of 0.

4.3.5 Objective 4: To determine the internal consistency of the SCICP for children with CP aged one to eight years.

Cronbach's alpha is used to determine the internal reliability of a test. It calculates the average of all possible split-half reliability coefficients. A score of zero means there is no internal reliability, whereas a score of one indicates perfect internal reliability of an assessment (Bryman, 2012). According to Table 4.15, the total Cronbach's alpha for the children with CP was 0,78 and 0,77 for the typically developing children. This indicates satisfactory levels of internal consistency for the test. For each domain, the alpha for both the typical and CP children varied between 0,71 and 0,78.

The individual domain scores represent satisfactory internal consistency levels of above 0,70. The overall score on the SCICP for both groups of children showed excellent internal consistency, with Cronbach's alpha values that were 0,94 and 0,93 respectively. The overall score is a promising indicator of excellent coherence of test items on the SCICP, demonstrating excellent levels of internal consistency (Tavakol and Dennick, 2011).

Table 4.15: Internal consistency using Cronbach's alpha for children with cerebral palsy and typical children total groups

	Children with cerebral palsy	Typical children
Total Cronbach's alpha	0,78	0,77
Domain		
Eating	0,73	0,74
FM Eating	0,75	0,75
Dressing	0,73	0,71
FM Dressing	0,78	0,77
Washing	0,75	0,75
FM Washing	0,76	0,76
Toileting	0,77	0,76
FM Toileting	0,76	0,75
Grooming	0,76	0,76
FM Grooming	0,78	0,77
FM Sleeping	0,77	0,77
General mobility	0,75	0,76
Overall score	0,94	0,93

4.4 Summary

The results of each age group according to the domains on the SCICP were calculated and compared for children with CP and the typical children. The median scores showed a difference in scores between the typical and the CP children. For almost every test domain for each age group, the children with CP had lower scores than the typical children that show a statistically significant difference. The younger children in the typical and CP children sample groups of one and two years, had scores that were not statistically significantly different.

Response process of the SCICP was confirmed as a significant correlation was found for the CP children's scores when correlated with their GMFCS and MACS

level scores. This indicates the assessment is related to the severity of the deficits caused by the condition of CP and not the child's age. Age, for the CP children, was not as strongly correlated with the SCICP scores. The correlation was moderate to strong when comparing the researcher's observations to the caregivers' report of their child's ability to complete a selection of self-care tasks. This correlation highlights some concerns of the validity of the caregivers' reports, or one-time observation of a child in a context that is unfamiliar to them.

The sensitivity, specificity and accuracy scores showed positive results; with high overall scores and positive and negative likelihood ratios indicating most children with CP require intervention.

Internal consistency of the tool demonstrated satisfactory levels of 0,78 for children with CP and 0,77 for typically developing children. Although the sample of each group was small, results from this study of children from a resource-constrained and low socio-economic, urban context living in the Ekurhuleni district in Johannesburg, has displayed promising results for the use of the SCICP within clinical practice.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter interprets and discusses the results obtained on the SCICP for two sample groups of children; the children with CP and typically developing children between the ages of nought to eight years. Demographic information and the medical history of both sample groups is described with additional factors included and discussed which affected the functionality of the children with CP. Validity of the SCICP is considered in terms of known-group validity, response process for the children with CP in terms of age, GMFCS and MACS levels and observation of a group of CP and typically developing children performing selected self-care tasks. The sensitivity, specificity and accuracy of the SCICP, as well as the internal consistency of the tool, are also discussed. Thereafter, the strengths and limitations of the study are considered.

5.2 Demographic and medical information

5.2.1 Demographics

A greater number of children with CP whose caregivers were recruited into the study were male. The children comprised of 30 males with CP, and 24 females with CP. Although the sample size for this study is too small to draw any conclusions from this difference in gender, it has been described in the literature that overall, there seems to be a greater prevalence of CP among males at a ratio of 1,3:1 (MacLennan, Thompson and Gecz, 2015; Omole *et al.*, 2018).

Within the current study, typical children ranged between the ages of nought to six-years-old, as six years is the age when self-care skills assessed on the SCICP are consolidated. However, a discussion paper by the World Health Organisation on early childhood development and disability (2012) states that early childhood can be defined as the time from prenatal development to eight years of age. The children with CP in the current study ranged between the ages of one to eight-years-old. Children with disabilities, including children with CP, often experience developmental delay and fall below the typical developmental trajectory (James, Ziviani and Boyd, 2014). Thus, the CP children's failure to achieve self-care skills

by the age of six years allowed for older children to be compared to the typical children of six years of age. Burg (2016) recommended that testing of the SCICP be done with both children with CP and typically developing children of broader ages in order to thoroughly assess the reliability and validity of the SCICP for children with CP.

The current study was completed on caregivers and children from a resource-constrained context from low socio-economic status homes and limited resources in terms of amenities. South Africa is considered to be a low to middle income country (LMIC), and a large portion of the population live in circumstances of moderate to extreme poverty (Pauw and Mncube, 2011). Globally, 85% of children with a disability live in LMICs with their disability exacerbated by poverty and only 5% having access to rehabilitation (Lagunju and Fatunde, 2009).

For this research study, the sample of caregivers of typical children and those with CP form part of a group of previously disadvantaged citizens of South Africa. Although the majority of participants have access to running water and electricity, they can be considered as living in resource-constrained conditions as 93% of CP children and 92% of typical children live in informal settlements close to six of the nine Ekurhuleni districts. Marutlulle (2017) wrote an article on the causes of informal settlements in Ekurhuleni Metropolitan Municipality and states the following: informal settlements are predominantly temporary structures built from basic materials. They lack one or more of the basic housing conditions; either adequate sanitation, quality water supply, lasting housing or adequate living space. The author further states that Ekurhuleni is one of the fastest growing areas in South Africa and is unable to provide adequately for the increasing demand for housing. The majority of informal settlements in the Ekurhuleni district are not situated on suitable land for housing (Marutlulle, 2017).

Although the majority of the typical (92%) and CP children's (87%) caregivers stated that they had access to water and electricity; the way in which these household amenities was accessed was not ascertained. Caregivers may have access to a tap located outside of the house or have intermittent access to electricity. Many of the homes in informal settlements do not have access to bathrooms inside the house. The self-care task of washing then would include collecting and boiling water for

bathing. Washing would then take place in a bucket inside the house. Thus, the living conditions of the children would affect how they perform their self-care tasks. The SCICP was developed for a rural, resource-constrained South African population in KwaZulu-Natal. Thus, the assessment tool takes contextual differences of performing self-care tasks into account.

Many of the participants are dependent on social grants due to high levels of unemployment and the cost associated with caring for a child, especially a disabled child. Only 29% of caregivers of the typical children and 46% of caregivers of children with CP were employed. These participants are amongst the more than 16 million people who benefit from social grants in the country indicating an annual income of less than R4800 and, therefore, a low socio-economic status (SASSA, 2016). Most unemployed caregivers received a care dependency grant for their child with CP while those with typical children received a child support grant. However, as reported by Gutura and Tanga (2017), in a study completed in the community of Ngqushwa municipality in the Eastern Cape, the social grant money received is insufficient to care for a child. This is especially true if they need to access health care and rehabilitation services regularly.

5.2.2 Medical history of children

The findings related to birth history showed little difference in birth mode between typical children and children with CP. Fifteen children with CP and 11 typical children were born prematurely. Over 40% of children with CP experienced birth complications including NNE, birth asphyxia, NNJ, prolonged labour, meningitis and foetal distress. Asphyxia was reported as the most common complication, which has been reported to be more commonly associated with CP in developing countries. Minocha, Sitaraman and Sachdeva (2017) found asphyxia contributed to 45.5% of cases and that prematurity accounted for 17.7% in a study in India. As in the current study, encephalopathy was the second most common risk factor for CP.

A range of types of CP as well as various GMFCS and MACS levels were found with 35% of children with CP presenting with spastic quadriplegia and a further 26% with spastic quadriplegia with elements of dystonia or hydrocephalus. Other studies in LMICs have supported these findings with a similar high percentage of children

presenting with spastic quadriplegia. Minocha, Sitaraman and Sachdeva (2017) found in their study in India that 56.6% of children in their sample were spastic quadriplegics and Omole *et al.* (2018) reported 69.5% of the sample in their study in Nigeria had spastic quadriplegia.

The GMFCS and MACS levels of the CP children from this study were varied, with most of the children accessing therapy found to be on a level IV or V on both classification scales. This is related to the higher percentage of spastic quadriplegics who have the most severe motor deficits and supports the study by Donald *et al.* (2014) that children with CP living in developing countries in Africa present with more severe disabilities. Omole *et al.* (2018) states that caregivers of children with CP with more severe deficits access clinics and hospitals for therapy services due to the child's associated problems such as cognitive impairments, epilepsy, sleeping problems, pain, bowel and bladder incontinence as well as visual and hearing impairments (Abas, Abdelaziem and Kilany, 2017; Almasri *et al.*, 2018; Omole *et al.*, 2018).

The co-morbidities found in the children with CP were hearing impairment, visual impairment and severe feeding difficulties that meant these children needed to be fed via PEG. Hearing impairment accounted for 7.4% of CP children and 5.6% of caregivers were unsure whether their child had a hearing impairment or not. Visual impairment accounted for 35.2% of CP children and 42.6% of caregivers were unsure of this. Children who needed to be fed via a PEG accounted for only four (7%) of the CP children. Epilepsy was the most frequent comorbidity (44%) and due to the majority of the CP children having GMFCS levels of IV and V, it was assumed that most children had some cognitive impairment. Research has shown that cognitive impairment and epilepsy are significantly associated with higher scores on the GMFCS (Dalvand *et al.*, 2012; Abas, Abdelaziem and Kilany, 2017). Furthermore, a higher percentage of children with these comorbidities are found in developing countries (Abas, Abdelaziem and Kilany, 2017).

The medical information for the children with CP confirmed that for many of them their condition was related to complications during birth and this resulted in a high percentage of children with severe motor deficits and spastic quadriplegia. According to literature, the severity of CP and comorbidities found in the sample in

the current study reflect those reported for developing countries (Couper, 2002; Cooper, 2015; Mathye and Eksteen, 2016; Omole *et al.*, 2018; Abdel Malek, Rosenbaum and Gorter, 2020). It can be assumed that the sample of children with CP was representative in terms of their medical information of a population of children with CP in a LMIC country and, therefore, a suitable sample on which to validate the SCICP.

5.3 The Self-Care Inventory for Children with Cerebral Palsy information

5.3.1 Objective 1: To determine the known-group validity of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay.

The first objective of the study was to determine the known-group validity of the SCICP for children aged nought to six-years-old who are typically developing, compared to those with CP, who may have developmental delay. Preliminary testing of the tool on a small sample revealed that the SCICP has the ability to identify differences in the typically developing children and the independence in the self-care abilities of children with CP (Burg, 2016). Thus, for this study, median scores on the SCICP were determined for the typically developing children and the difference in the scores of the children with CP were established to indicate if the tool could identify deficits in their self-management ability.

It was found that scores for all domains on the SCICP increased for each age group from one to six years with the exception of eating and functional mobility associated with eating at five years for the typical children. This confirmed the SCICP did asses changes in independence in self-care based on age (Burg, 2016). The problems found with the five-year-old group may have reflected the very small sample of four-year-olds in which one participant had high scores. This component needs to be further assessed. As expected, the self-care ability of the CP children did not align with their age but rather with the severity of their motor dysfunction as discussed below. The SCICP is similar, therefore, to the PEDI, which also provides an indication of how the child is performing relative to what they should be doing at an expected age. Furthermore, the PEDI also includes self-care tasks that are

relatively easy to relatively difficult for items in each of the domains (Knox and Usen, 2000).

All scores for the children with CP fell below those of the typically developing children. Statistically significant differences were found between the group of typically developing children when compared to the group of CP children for the scores across most test domains and age groups. Scores on the SCICP for the one-year-old group of typical children and children with CP, however, did not display as significant differences. This finding is in keeping with literature, indicating that limited independence is found in all children under the age of one year (Öhrvall *et al.*, 2010). Children of this age are typically dependent on caregivers for assistance with all self-care tasks so the difference between typically developing children and infants with CP is not as marked (Öhrvall *et al.*, 2010). However, even at one year of age, the children with CP have significantly lower scores for washing, grooming, sleeping and general mobility as they had less motor and cognitive ability to assist with self-care.

The differences in scores were significant as the children increased in age; gradual independence is achieved in self-care activities as there is accelerated development of hand function and fine motor skills. From the age of two years, independence in self-care tasks is enhanced over time due to increased opportunities to practice and develop these skills (Kim, Kang and Jang, 2017). Significant differences were found for all domains of self-care for all age groups from two to six years for typically developing children and children with CP with the exception of toileting for the four-year-old group ($p=0,11$). This may have been due to the very small four-year-old typical sample group ($n= 3$). This result needs further investigation as within the four-year-old sample of CP children; one child had a GMFCS of level I, a MACS level of II and had high scores on the SCICP, which affected the results found.

When the minimum and maximum scores and 95% confidence interval scores were considered, there was limited ceiling and floor effects found. None of the median scores for any domains reflected zero, which indicated that children with very low ability could still be assessed on the SCICP. Ceiling scores were achieved by typical children of six-years-old for the domains of functional mobility associated with grooming, sleeping and general functional mobility achieved by two to three years.

However, except for functional mobility associated with sleeping, the children with CP achieved none of these ceiling scores since motor function and mobility is one of the main deficits associated with this condition. Therefore, the scoring on the SCICP for all domains is appropriate to identify deficits in children with CP between the ages of six months and eight years and six-months-old.

The current study has compared typically developing children's scores as a norm of comparison against children with a confirmed diagnosis of CP and developmental delay. The known-group validity of the SCICP has been shown to be adequate in relation to the age of children and the tool can identify deficits in children with CP who are unable to achieve self-care tasks at the same level as their typically developing counterparts. The scores for the CP children from resource-constrained contexts can be compared to the median scores for typical children, matched for age, in order to determine the extent of developmental delay when compared to functional expectations of that age. This can be used to guide intervention in self-care for children with CP, although further data is required on larger groups for each age band to determine standard scores for the SCICP. This study only provides preliminary normative scores as medians for each age group from nought-years-old to six-years-old of typical children from poorly resourced areas.

5.3.2 Objective 2: To determine the content validity (response process and relationship to other measures) of the SCICP for children aged nought to six years who are typically developing, compared to those with CP who may have developmental delay.

5.3.2.1 Response process- Observation of the child

The response process of the SCICP was further assessed by determining the correlation between scores provided by the caregivers for dressing tasks and the scores given by the researcher when observing the children completing these tasks. The correlation between researcher and the caregivers of the CP children was of moderate strength. For the more severely affected children, researcher and caregiver scores were similar but discrepancies in scores were noted for the children with lower GMFCS and MACS levels. The researcher often scored the child's ability to perform the task as less than the caregiver had scored them.

Caregivers of typically developing children had scores closer to those of the researcher with a strong correlation achieved for this group.

These findings raise two concerns; firstly, literature indicates that self-care tasks are a product of the caregiver's expectations and that caregivers may wish to indicate their child can achieve more than they actually do as they find it difficult to accept their child's limitations. The child's level of motivation to perform the task may be different due to the fact that the different context in the Occupational Therapy department may have negatively affected the child's ability to complete the task, thus, increasing the amount of caregiver assistance needed during the time of assessment (Abubakar *et al.*, 2010). In some cases, scores might differ between caregiver and therapist due to time constraints. If the caregiver is in a hurry, they tend to perform more aspects of the self-care task for the child. Differences in ability of a child to complete a self-care task has been attributed to different settings and the caregiver being able to observe the child over time, whereas the therapist in this study was only able to have a one-time observation of the child's abilities. Children, especially those with disabilities, may also use different forms of mobility in different contexts and over different terrains. This cannot be observed by the therapist in the clinic (Tieman *et al.*, 2004).

The second concern is the validity of caregiver report questionnaires such as the SCICP. In the current study setting, it was clear that some caregivers did not find completing the SCICP easy and, thus, more of an interview was conducted with a number of caregivers. This made the process very long for some caregivers, which may have affected their contribution to the process of providing information. A study by Rich, Rigby and Wright (2014) reported that completing a long self-care form such as the PEDI may provide a positive experience but most caregivers found it discouraging and experienced negative reactions if their children were unable to perform most of the items on the assessment. This reinforced how much assistance their child required and many felt that it was difficult to judge this according to the scale for scoring of what their child was willing to or could do. This may account for the greater discrepancies seen in the scores between the researcher and the caregivers of the children with CP. In their study, Elad *et al* (2013) found significant differences between mothers' and rehabilitation professionals' scores using the

PEDI on capability and performance in self-care of children with CP. Mothers scored their child's functional mobility higher than the therapists did. These differences could be due to the fact that mothers understood their children better, particularly regarding performance in the home environment.

Abubakar *et al* (2010), found caregiver reports in low socio-economic settings to be an effective assessment method for obtaining information. The use of a caregiver report questionnaire, which was filled in by the caregivers of the typically developing and CP children, has advantages and disadvantages. The advantage is that the questionnaire allows for comment on each item, but a disadvantage is that even with this addition, it is difficult for the therapist to elicit detailed responses and there is less control over how the questionnaires are filled out. Thus, after the experience in the current study where some participants required assistance to fill out the SCICP, it is suggested that there be a possible addition of a semi-structured interview section added to the SCICP. The therapist would then more easily be able to determine challenges or strengths related to the child's ability to complete their self-care tasks independently. This would provide an enhanced understanding of the occupational profile of the child and, thus, enhance goal setting and intervention with the caregiver and their child.

Discrepancies between the caregivers' and therapists' assessments were also reported by Abubakar *et al* (2010), which they attributed to the caregivers' lack of knowledge regarding developmental milestones. This was supported by Davies *et al* (2017) who stated that differences in caregivers understanding of the child's functional performance is associated with their knowledge and understanding of child development. This lack of understanding is greater for children with disabilities, as found in the current study. Caregivers usually have knowledge about normative milestones for independence in daily activities within their culture, but do not know the accepted standards of functioning for children with CP. Caregivers of children with CP have to explore and discover what their child can do considering the variability of the child's physical and cognitive impairments. Thus, it may be more difficult to clearly report their child's abilities in a caregiver report questionnaire (Elad *et al.*, 2013).

Authors, however, indicate that even with these discrepancies, children with deficits who require therapy can still be identified through the use of caregiver report questionnaires. The questionnaires are cost effective and also increase awareness amongst caregivers about their child's development and the amount of assistance they give their child (Abubakar *et al.*, 2010; Rich, Rigby and Wright, 2014).

5.3.2.2 Relationship between variables -Level of function, age and self-care

The prognosis for self-care abilities and mobility in children with CP can be based on GMFCS levels (Smits et al., 2019). Gunel et al (2009) also found this in their study with CP children under the age of seven years. In the study, the authors found a strong correlation with GMFCS and MACS levels associated with functional self-care skills. Lower GMFCS and MACS levels showed a greater degree of skill in self-care and mobility areas. Therefore, as suggested by Kim, Kang and Jang., (2017) and Öhrvall *et al* (2010) the correlation between GMFCS as well as the MACS levels and self-care scores on the SCICP, such as those found in the PEDI, support the content validity of the self-care tool.

In the current study the SCICP scores of the children with CP had a negative moderate to strong correlation with their GMFCS levels. This indicates that motor function is associated with the children's ability to carry out self-care tasks, especially functional mobility for each task as all functional mobility domains had a strong correlation with the GMFCS scores, except that of dressing. The functional mobility items on the SCICP includes moving around the environment and reaching for items.

These findings support those of Kim, Kang and Jang, (2017) and Öhrvall *et al.*, (2010) who found a significant relationship between GMFCS levels and self-care functional mobility. They found that the mobility score on the PEDI was the only significant factor influencing self-care ability in children with CP. As in the current study, this included mobility in performance of self-care or what an individual actually does in their environment daily. This includes their gross motor capacity related to performing in a specific environment. In the SCICP this includes washing in a basin and bowl, using a toilet situated outside of the house and, thus, outdoor mobility. Outdoor mobility, however, did not include the use of stairs.

Low to strong correlations were also found between the SCICP scores and the MACS levels in the current study. This supports the findings of a number of researchers who highlighted the impact of the MACS levels on a child's ability to effectively carry out their self-care tasks (James, Ziviani and Boyd, 2014). Unlike studies by Gunel et al (2009) who found a strong correlation with MACS and functional self-care skills for children with CP under the age of seven on the PEDI, not all self-care domains in the current study had a strong correlation. However, the lower the MACS level, the better the child's performance was in self-care tasks that required hand function such as dressing, washing and grooming (Kuijper *et al.*, 2010; Öhrvall *et al.*, 2010).

Unlike the PEDI, which has two separate sections for self-care and mobility, the SCICP includes functional mobility items related to each self-care domain. Each domain, for example, eating, has a functional mobility component associated with that task. The strong and moderate correlations found in the current study for these functional mobility sections on the SCICP and MACS levels, is due to the functional mobility items in these domains, especially eating, washing and general mobility including aspects that require hand function. A number of these items such as 'carries plate of food to the table', 'opens juice bottle', 'uses soap and cloth', 'carries objects large enough to require two hands' require hand function, which is also associated with independence in self-care (Chien *et al.*, 2014).

A low correlation was found between the age of children with CP and their scores on the SCICP. Öhrvall *et al* (2010) stated that age correlated with independence in self-care tasks only when children presented with GMFCS and MACS on levels II and I. Since the majority of the children in the current study were on GMFCS and MACS levels III to V, their self-care ability was not expected to correlate with their age, but with their functional ability as discussed above. The GMFCS and MACS levels of the children are also indicative of their cognitive, hearing and visual impairments, which may have an effect on the child's ability to effectively carry out their self-care tasks supporting the associations found in the current study (James, Ziviani and Boyd, 2014).

The findings for the factors considered in content validity of the SCICP are supported by research in a similar assessment of self-care and functional mobility

required for self-care. The discrepancies between the caregivers' and researcher's scores, especially for the children with CP, have previously been reported and should be considered when setting intervention goals with the caregivers (Elad *et al.*, 2013). The validity of the domains and items on the SCICP in relation to motor function was found. However, due to the inclusion of hand function in tasks in the functional mobility sections of the domains, this validity was less so for the MACS levels. However, the correlations in the current study were significant and it was accepted that the SCICP is valid in relation to the functional levels of the children with CP.

5.3.3 Objective 3: To determine the diagnostic accuracy in terms of sensitivity, specificity of the SCICP for children with CP and typically developing children aged one to six years

The known-group validity findings in the current study support the potential of the SCICP to differentiate between a typically developing child and a child with CP. The sensitivity, specificity and accuracy of the SCICP were determined according to the lower band of the 95% confidence intervals for the overall scores for each age group.

The SCICP showed high levels of sensitivity at 87,5% and specificity at 74,4% overall with an 80% accuracy level in identifying self-care deficits and developmental delay in children with CP correctly and not classifying typically developing children with self-care deficits. The sensitivity score in identifying deficits and developmental delay is similar to the score reported for the WeeFIM on children with CP at 86,6% but the specificity is lower than the 82,2% reported by Bagley *et al* (2007). This was affected by the results for children in the one-year-old age band who were identified as dependent, which should be considered normal at this stage of their development. Therefore, the scoring of these age bands may need to be adjusted as accuracy scores are at 69% for this age group. The SCICP, like the WeeFIM, demonstrated better levels of sensitivity for identifying children with CP with deficits and developmental delay. All other age bands had accuracy scores over 78%. The scores for each age group indicated an increasing accuracy, as the children got older. The typically developing children became more independent with 100% accuracy achieved in identifying the groups correctly for the presence or

absence of deficits and developmental delay for the six-year-old age band. The five-year-old age band had a lower score than the four-year-old age band, which again may be due to the inadequate number of typically developing four-year-olds.

For each age group, significant positive and negative likelihood ratios were below and above a score of one indicating the tool is clinically useful at identifying deficits and developmental delay in a population of children with CP. Overall, the SCICP showed high levels of sensitivity, specificity and accuracy for each age group, except in the one-year-old group. The levels of sensitivity and specificity reflect the dependence in self-care of younger children, which was not accommodated for by the SCICP.

5.3.4 Objective 4: To determine the internal consistency of the SCICP for children with CP aged one to eight years.

Reliability is influenced by a number of factors; characteristics of the test such as the length, item quality, difficulty of the items, circumstances surrounding testing such as the instructions, the person completing the test, the time taken and the participants who should be from a homogenous group (Traub & Rowley, 1991). Reliability is increased as the test length increases, however, participants are reluctant to fill in long questionnaires. Thus, the tool needs to be of an appropriate length yet well-developed in order to enhance participant responsiveness and reliability of the assessment tool (Nunnally and Bernstein, 1994).

As suggested, the Cronbach's alpha was calculated for each of the domains as well as for the entire test, or scale, as the entire scale score may be inflated. There are different reports about the acceptable values of alpha, ranging from 0,70 to 0,95. Values between these ranges are considered to be at an acceptable level of internal reliability. Scores higher than 0,95 may indicate redundancy of items and repletion in the scale (Tavakol and Dennick, 2011). An alpha of 0,7 is deemed "satisfactory", 0,8 is "good" and above 0,9 is "excellent" (Bryman, 2012).

Internal consistency refers to how closely related items on a test are and how well they measure what they are supposed to measure (Bryman, 2012). As the SCICP is measuring self-care and functional mobility related to self-care, all test items should have a strong connection to the construct being measured (Bolarinwa,

2015). The total Cronbach's alpha for the children with CP was 0,78 and 0,77 for the typical children. All scores for each domain were above 0,7 for internal consistency of the tool. These results are similar to those reported for the PEDI where self-care had an alpha score of 0,72 and functional mobility had a score of 0,70 (Haley *et al.*, 1992). Thus, it can be accepted that the internal consistency of the SCICP is adequate in its present form.

5.4 Strengths and limitations of the study

5.4.1 Strengths of the study

Anaby *et al* (2017) stated that integration of child participation in therapy practice is unclear and that therapy goals should be in line with actual activity participation. A recent systematic review within the study done Anaby *et al (*2017) showed that interventions with CP children showed improved outcomes when goals were based on thorough assessment that focused on the children's level of activity participation. This strengthens the need for the SCICP as a contextually relevant assessment tool for the South African population, which focuses on participation, rather than body functions and structure when determining limitations in functioning.

Assessment items were checked for content validity after the SCICP was developed, which ensured contextual and linguistic appropriateness of the test items. The SCICP was available in isiZulu, Sesotho and English. The tool was inexpensive to administer and could be answered in a caregiver report format in a language familiar to the caregiver, enhancing the tool's usability in the clinical setting.

The target population should be representative of the individuals the tool is intended to measure. The SCICP was administered to children from resource-constrained and low socio-economic South African contexts. Although children from this sample came from an urban population, culturally, linguistically and contextually, they shared many similarities in terms of the methods of completing self-care as those participants described by Burg (2016) in her more rural and peri-urban sample.

The study also provides a starting point for normative data for typically developing children against which deficits and development delay in children with CP can be measured.

5.4.2 Limitations of the study

The information regarding socio-economic status collected from the caregivers of the typically developing, as well as children with CP, within this study was limited. Caregivers were asked only whether they were employed or not and no information regarding the household's annual income was obtained. Although caregivers were asked about access to resources, it was not established whether these were within their homes or what type of homes they lived in. However, it was ascertained that the majority of the children who took part in the study lived in informal settlements in the Ekurhuleni district. Thus, it can be assumed based on the research done by Marutlulle (2017) and Ekurhuleni Metropolitan Municipality (2016) that generally, living conditions in this district are of a poorer condition. Furthermore, as the majority of children received social grants, it can also be presumed that most caregivers received an annual income of less than R4800. This indicates a low socio-economic status. Inferences were made based on the information above. An implication of this is that the researcher's understanding of the extent of how the resource-constrained environment affects the participants is limited. Thus, a completely accurate and holistic understanding of the children's environments was not obtained.

The inclusion criteria for the typically developing children stated that there should be no reported disability. However, access to all of the participants' hospital files could not be obtained. Thus, some of the birth complications of the participants might have been missed. Birth complications could indicate an impact on normal development, thus affecting the timely acquisition of developmental milestones of the typically developing children. This could have had an effect on the typical children's results.

The long length of the SCICP meant that certain caregivers were reluctant to fill in the form. Although the level of education of the caregivers was not ascertained, it is speculated that the lower the level of education and the less proficiency with regards to reading and writing ability, the less able the caregivers were to complete the

SCICP independently. This meant that the researcher, or research assistant, needed to be present for a greater portion of time whilst the assessment was being administered. This decreased the amount of assessment forms that could be administered at one time. This limited the number of questionnaires that could be administered at any given time. The length of the questionnaire and possible low levels of literacy may have affected the caregiver's understanding of the assessment. This could have impacted on the quality of completion of the SCICP, which may have impacted on the results.

The scores for the one-year-old groups of typical and CP children did not show statistically significant differences for the majority of the test domains on the SCICP. This is because one-year-olds are developmentally dependent on their caregivers for assistance with most self-care tasks. This means that the SCICP is not valid or reliable for the one-year-old age group. The implication of this is that testing of children with suspected developmental delay can only be performed from two-years-old and up.

Previous studies have noted that cognitive impairment has a significant impact on children's ability to complete their self-care tasks. This question was not formally asked of caregivers of children with CP. However, based on the severity of CP, reflected in the children's GMFCS and MACS levels, as well as the presence of epilepsy, it was assumed that the majority of the participants had cognitive impairment. This study did not specifically explore the impact of associated impairments on the CP children's ability to perform their self-care tasks. The assessing therapist needs to determine both the physical and cognitive dysfunction of the child so as to accurately identify the reasons for the child's poor or limited performance on the SCICP. As stated by Burg (2016) the functional classification systems can and should be used in conjunction with an assessment like the SCICP that explores participation in occupations. These and additional cognitive or visual-perceptual assessments may be used to supplement assessment information drawn from the SCICP. This will provide a holistic understanding of the child's overall functioning and improve goal setting and adaptations that need to be made during intervention.

There is a lack of stratification in terms of age groups of the sample. This resulted in small sample groups, especially for the four-year-olds, which affected the results and normative medians for this age group. This may have resulted in a type II error whereby significant correlations may have been missed.

The small sample size for both the typical and CP children groups means that these results cannot be extrapolated or applied to the whole population. It does, however, provide a starting point for normative data. The findings from the overall median scores of the typical children can be used to compare CP children's scores of similar ages. Differences in these scores could indicate developmental delay and would need to be investigated further.

5.5 Clinical implications

The practical use of the SCICP in clinical situations will be described below, along with other clinical implications for its use:

This study had a relatively small sample size. Thus, the overall median scores from the typical children's results may be used as a guide for measuring children with CP's performance on the SCICP using their overall score on the SCICP. As the tool does not reflect valid or reliable results for the one-year-old group, CP children with suspected developmental delay should only be assessed using the SCICP from two-years-old up to eight-years-old. CP children up to the age of eight may be assessed as they often fall below the typical developmental trajectory. The overall median scores for the two-year-olds is 298, for the three-year-olds it is 393, for the four-year-olds it is 399, for the five-year-olds it is 410,5 and for the six-year-olds their overall median score was 435. Assessing therapists can use these scores to provide an indication of how a CP child of a similar age is performing according to their typical peer.

Scores of the CP children should be interpreted with caution, however, due to the fact that a type II error may have occurred in the four-year-old group. Comparisons made between a CP child's overall score on the SCICP against a typical child's overall score from the same age group should be used as an indication of possible developmental delay. This assessment should not be used in isolation. It is recommended that the SCICP be used in conjunction with other physical and

cognitive assessments so as to provide a holistic understanding of the child's overall functioning.

The functional classification systems, the GMFCS, MACS, EDACS and CFCS can be used to gather more assessment information on the child's participation and level of independence in their self-care activities. Cognitive or visual-perceptual assessments should also be conducted to determine the impact of any cognitive impairments on the child's participation in their self-care tasks. Furthermore, visual assessments can be conducted by the assessing therapist to determine the impact of visual impairment on the child's functioning. Referrals should be made to the relevant health care professionals such as speech-language and hearing therapists for feeding concerns, to the audiologist for any hearing concerns and to the ophthalmologist for further visual impairment investigations. Referrals to physiotherapy should be made for any lower limb, hip or spinal related problems.

Due to the long length of the SCICP and the expected lower levels of education and literacy among caregivers, the implication of this is that the assessing therapist may need to administer the SCICP as a semi-structured interview rather than a caregiver report questionnaire.

As there was only a moderate correlation between the researcher's scores and those of the five caregivers of the CP children that were observed, it is recommended that the assessing therapist observes at least one self-care task of each test domain so as to ensure that caregiver report of their child's self-care participation is accurate.

As a result of the two aforementioned guidelines to therapists administering the SCICP, the assessing therapist will need approximately 45 minutes to one hour to administer the SCICP per caregiver and child. This should be done on an individual basis.

Furthermore, therapists who will be administering the SCICP should be familiarised with the assessment tool and should observe the assessment being administered by a more experienced therapist before conducting the assessment with caregivers and their children themselves.

Lastly, as the authors in the study done by Davies *et al (*2017) suggested, if possible, the assessment form should be given to caregivers to go through a few days prior to completing the assessment so that they are aware of test items and can more accurately observe their child's performance in each activity domain before completing the questionnaire with the therapist.

5.6 Summary

In summary, the SCICP has proven to be a reliable and valid tool with regards to known-group validity, components of content validity, internal consistency as well as diagnostic accuracy based on sensitivity and specificity.

Known-group validity was verified as all median and 95% confidence interval scores for the typical children were higher than that of the children with CP in each age group for each self-care test domain except for the one-year-olds and for one domain for the four-year-olds.

Components of content validity in terms of relationship of variables on the SCICP were confirmed by scores for the children with CP, which correlated strongly with their functional ability according to their GMFCS and MACS levels. Response process was established by observation of the children's actual performance. Results revealed that in most cases, caregiver report and therapist observation for the typical children were similar. However, there were discrepancies for the scores of the caregivers of the children with CP and the therapist's scores. This could have been influenced by the different context in which the child performed the task, the caregivers' lack of knowledge of developmental milestones and a different understanding of their child's capabilities.

The diagnostic accuracy of the assessment was acceptable at 80% based on the sensitivity and specificity results, which showed that the SCICP is able to identify children with CP and does not identify typically developing children (Mandrekar, 2010). The low accuracy and specificity and sensitivity for the one-year-olds indicate scoring for this age group may need to be adjusted.

The likelihood ratios for this test also accurately identified children who require, and who would not require, intervention. The total Cronbach's alpha was above 0,7 for

both the children with CP and typical children reflecting satisfactory levels of internal consistency for all domains of the SCICP.

The SCICP has reflected adequate construct validity in terms of known-group validity and internal consistency levels.

CHAPTER 6: CONCLUSION

6.1 Main findings of the study

As many assessment tools used for the South African population are based on Westernised tools, which often are misrepresentative of our population, Burg (2016) developed the SCICP so as to enhance cultural and contextual appropriateness of test items for determining the extent to which children with CP living in resource-constrained areas are able to complete their self-care tasks. Many authors state that accurate assessment is needed for appropriate intervention (Burg, 2016; Gladstone et al., 2010; Matafwali & Serpell, 2014).

Development of the SCICP underwent a number of processes; items were based on a review of existing assessment tools, and then generated and adjusted according to SMEs and caregivers. Thereafter, content validity of the tool was established and piloted on a sample of five typically developing and five children with CP from rural and peri-urban South African contexts. Burg's (2016) pilot study showed promising results for widespread use of the SCICP for a South African population, however, she recommended that the tool undergo further validity and reliability testing in order to confirm the clinical usefulness.

By establishing the known-group validity, other components of content validity and internal consistency of the SCICP, the use of the assessment tool will be enhanced, thereby increasing the utility and technical adequacy of the tool as it becomes standardised for young children with CP (Glover and Albers, 2007). This process is essential for use in the clinical setting. Once the SCICP has been adequately validated for the target population, assessment results can be used to design intervention goals for self-care that are appropriate for a child with CP from similar contexts (Mailloux *et al.*, 2007; Harvey *et al.*, 2008; James, Ziviani and Boyd, 2014).

The results from the study showed the scores of the typically developing children increased steadily with an increase in age within each domain of self-care on the SCICP, including their overall point score. A significant difference was found between these scores and those achieved by most of the CP children, with the

exception of the one-year-old group of children. This confirmed the difference between the two groups and the known-group validity of the SCICP. Some concerns with ceiling effects were noted for typically developing children, however, this did not affect the scoring for children with CP up to eight years of age. This allowed for self-care deficits and development delay to be identified in these children.

When the relationship between variables of the SCICP for children with CP was with their age and functional classification was determined, the results indicated, as in other research, that there was a correlation between self-care and the children's GMFCS and MACS levels. The GMFCS scores had a stronger correlation with the SCICP scores since these items placed emphasis on functional mobility. Many of the functional mobility domains on the SCICP also had items, which required unilateral and bilateral hand function. Thus, correlations for the MACS within the functional mobility domains were also strong. The items in the self-care domains and the functional mobility sections associated with each self-care domain may need to be reviewed in light of this aspect, although other results in the study do confirm the validity of the SCICP.

In terms of the response process the caregivers of typical children and the researcher's observation scores were relatively similar. However, there was only a moderate correlation between the researcher's and the caregivers' scores for the children with CP when the researcher observed some self-care items. This finding has been reported by other researchers that differences are likely due to the fact that children with disabilities do not perform at the same level in unfamiliar contexts and that caregivers' lack of knowledge of developmental milestones may affect their assessment of their child's functional performance.

Sensitivity and specificity of the test scores were found to be acceptable for the overall, as well as for each age groups, score with the exception of the one-year-old age group. Scoring for this age group needs to be reassessed to accommodate for the dependency of typical children at this age. As the age of the children in the two samples increased, and the gap between the typically developing children and the CP children became larger, the sensitivity and specificity of the test also improved. These results also showed significant positive and negative likelihood

ratios for the identification of self-care deficits and developmental delay in children with CP.

The SCICP also demonstrated high levels of internal consistency across all of the test items for both the children with CP as well as the typically developing children. This indicates the SCICP has adequate reliability for this aspect.

The SCICP has shown promising results with regards to the aspects of reliability and validity studied within this research report. It shows good potential for clinical use as a standardized tool within the South African context for a low socio-economic population of children with CP.

6.2 Recommendations

Although the reliability and validity of the test has been measured based on predominantly caregiver report, it might be necessary to administer the SCICP as a semi-structured interview. This will assist those caregivers with lower levels of literacy by guiding the process of completing the form. Therapists should also ask to observe the child performing at least one self-care task in some of the test domains to verify caregiver's answers.

It is recommended that 45 minutes to one hour is allowed for the assessment. Once the SCICP has been administered with the caregiver and the test is scored, other physical and cognitive assessments should be conducted to obtain a holistic picture of the child's functioning.

It is recommended that CP children between two-years-old and eight-years-old can be assessed using the SCICP. Scores obtained for CP children on the SCICP should be measured against the overall median scores of the typical children aged two to six-years-old. This comparison should be made with caution as the SCICP is not a diagnostic tool. The typical scores should act only as a guide for typical development.

Once all assessments have been conducted, a feedback session can be held with the therapist and caregiver to discuss factors impacting the CP child's self-care performance. Once this feedback session has been held with the caregiver, collaborative goal setting can be completed to address intervention goals.

Intervention goals decided on with the caregiver, and where possible, the child, will assist the caregiver to enhance the self-care abilities of their child. Improvements in the child's self-care functioning can be measured and recorded by administering the SCICP in the future.

It is also recommended that a more comprehensive demographic questionnaire be included for supplementary assessment information for future research studies. Information regarding the caregiver's level of education can be obtained as well as more information regarding access to resources and household amenities.

It has been shown from the results drawn from this study that the SCICP shows promise of being used in clinical practice as a contextually relevant assessment tool to accurately determine the self-care abilities of children with CP. As this was only the second step in the standardization of the assessment tool, further recommendations can be made with regards to this. More aspects of the tool's reliability and validity should be explored and studied. A larger sample size should be studied with correct stratification of each age group. This stratification of the sample needs to be done for both the typically developing and CP children.

Further stratification of the CP children sample should be done in order to provide information regarding a specific number of children with each classification level on the GMFCS and MACS. These, along with associated impairments in the CP children group, should be studied so as to more clearly determine the impact that these additional factors have on a child's ability to complete their self-care tasks.

As many of the caregivers commented on the length of the SCICP, it is recommended that a shortened version of the form be created, once further reliability and validity testing has been done. Furthermore, instructions for the completion of the SCICP could be more detailed. An example should be provided for each section on how to answer that section's question. For example, the Likert scale (1-4) could be quantified with a pictorial example to explain what "a lot of help", "a little bit of help" and so on from the caregiver means when assisting children to complete their self-care tasks.

There should also be a section included that highlights any strengths of the child when completing their self-care tasks and provide examples of what these strengths

might be; for example, the child might point to and choose which clothes they want to wear, even if they are unable to put their t-shirt on independently. In addition to a strengths section, a challenges section could also be included. For example, the child's ability to complete their self-care tasks may be influenced by the caregiver's lack of time letting the child try to perform the task, or perhaps a different caregiver helps the child on different occasions so the child doesn't have the opportunity to learn how to do the tasks him or herself.

Furthermore, standard scores need to be developed for the SCICP to provide a more realistic clinical picture of the child with a disability. This will ensure that the child's functional performance is rated with regards to their ability to complete the task within the test domain, and compared to expectations of task performance rather than compared to their chronological age.

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APPENDIX A DEMOGRAPHIC QUESTIONNAIRE

The Self- Care Inventory for Children with Cerebral Palsy

Form 1: *Demographic Questionnaire*

Name of child/ Igama lengane/ Lebitso la Ngoana:	Name of caregiver/ Igama lomnakekeli/ Lebitso la mohlokomedi:
Contact details of caregiver/ Izinamba zomnakekeli/ Nomoro ea mohlokomedi ea mohala:	Address/ Ikheli/ Tulo:
Child's date of birth/ Usuku lokuzalwa lwengane/ Letsatsi la matsoalo a ngoana:	*Please circle the applicable one below:* Child WITH cerebral palsy/ Child normally developing Ingane evamile/ engavamile Haeba ngoana ale "Atypical" (CP), e kaba o nale CP e joang? If child has CP, what type of cerebral palsy does child have?/ Umangabe ayivamile ingane, inokukhubazeka ebucosheni okunjani okubizwa nge cerebral palsy? _____
Birth history/ Umlando wokuzalwa kwengane/ Histori ea matsoalo: *Please circle the following or write out* • Natural birth/ C-section • Born full term or at _____ weeks • Any illnesses or birth complications? _____ _____	Developmental history/ Umlando wokukhula/ Histori ea ho hola ha ngoana: *Please state at what age the child performed the following* • Rolling _____ • Sitting_____ • Crawling_____ • Standing_____ • Walking_____
Medication child takes/ Imithi ephuzwa ingane/ Meriana eo ngoana ae nkang:	*Please circle the appropriate answer:*

	Does child have epilepsy/ Ingane inaso isifo sokuwa na/ E kaba ngoana o nale *epilepsy*? Yes/ No
Do you have running water and electricity/ Ninawo amanzi no gesi/ Mohlokomedi oa sevetsa/chee? U sebetsa mosebetsi o joang? Yes/No	Is your house close to a road/ Indlu yakho isondelene somgwaqo na? /Le hae la hau le haufi le mmila oa dikoloi? Yes/No
Caregivers employed/unemployed?/ Umnakekeli uyasebenza yini? Yes/No If yes, how many people in the household are employed? _____ If employed, what work do you do?/ Umangabe uyasebenza, wenza muphi umsebenzi?	Does child receive a grant? If yes, name of grant?/ Ingane iyayihola imali kahulumende? Umangabe iyahola, ihola yiphi?/ Na ngoana u fumana igrant? Haedba ae fumana u thola e fe?
GMFCS level: ***To be filled in by therapist***	**MACS level:** ***To be filled in by therapist***
Age child started attending therapy/ Ibinangakhi iminyaka ingane uma iqala i therapy/Dijara tsa ngoana tsa ho qala therapy:_____ ***Only applicable to children with CP***	Hearing loss: Yes/ No Inkinga yokuzwa ngezindlebe : Yebo/cha Ua utiua/ chee?
Visual impairment: Yes/No Inkinga yamehlo: Yebo/cha Mohlo a ngoana a nale CVI/kappa chee?	Eating and drinking: Orally/ PEG Ukudla : Ngomlomo/ngephayiphi Ho ja le ho noa: U sebedisa molomo/ PEG

APPENDIX B SELF-CARE INVENTORY FOR CHILDREN WITH CEREBRAL PALSY (SCICP)

Administration

- Ask parent or caregiver whether their child can perform each item independently.
- If the child is unable to perform the item independently, ask the parent or caregiver how much help the child needs to perform this task and what kind of help the child needs to complete this task.
- Observe the child perform each item.
- Score based on observation, using table below.
- If the performance and caregiver report differs make notes in the comments section.

Scoring

Score Number	Score Description
1	Child is unable to do the task at all Ingane ayikwazi nhlobo ukwenza umsebenzana *Ngwana ha a kgone ho etsa mosebetsi*
2	Child is almost able to do the task, but needs a lot of help Ingane iyakwazi ukwenza umsebenzana kodwa idinga ukusizwa kakhulu *Ngwana o batla a leka ho etsa mosebetsi, empa o hloka thuso e ngata* • Help is from caregiver; environmental support and adaptations; standing frame; chair; walker; facilitation • Okuvela kumnakekeli, ukusekela futhi ukuguqula isimo sendawo ekuyo, uhlaka lokuma, isihlalo, insiza yokuhamba, ukumsiza • *Thuso e tswa ho tshehetso ya mohlokomedi; wa tikoloho le maemo a feto-fetohileng; standing frame, setulo, setsamaisane*
3	Child is almost able to do the task on his own, but requires a little bit of help Ingane icishe yakwazi ukwenza umsebenzana kodwa idinga ukusizwa kancane *Ngwana o batla a atleha ho etsa mosebetsi ka boena, empa o hloka thuso e nyenyane* • Help is from built up spoon; modified Velcro fastenings; extra time; universal cuff • Kusukela esipunini esakhiweyo, okokufasa okujikwe kwafaneleka, isikhathi esithe esithe xaxa, okufakwa esihlakaleni okujwayelekileyo • *Thuso e tswa ho kgaba e ahuweng, modified Velcro fastening, nako e ekeditsweng, universal cuff*

4	Child is able to do the task without any help Ingane iyakwazi ukwenza lo msebenzana ngaphandle kosizo *Ngwana o kgona ho etsa mosebetsi ntle ho thuso leha ele efe.*

		Items	Scoring				
	Age of Indepen-dence (years)	**Eating Items**	**1**	**2**	**3**	**4**	**Comments**
1	2	**Ugwinya uketshezi ngaphandle khwehlela;** ***Ho noa dino ntle le ho hohlola*** Swallows liquids without coughing					
2	2	**Udla ukudla okubushelelezi okuthambile;** ***Ho ja dijo tse boreledi*** Eats smooth soft foods					
3	2	**Usebenzisa iminwe uma edla;** ***Ho sebedisa menoana hoja*** Uses fingers for eating					
4	2	**Udla ukudla okugayiwe/izigaxa;** O ja ditswa mobung Eats ground/lumpy foods					
5	2	**Uphakamisa inkomishi khona ezophuza** ***O phahamisa kopi ho nwa*** Lifts cup to drink					
6	2	**Uyaliluma iqhuzwana lokudla;** ***OnNgoatha dikgechanas tsa dijo*** Bites off piece of food					
7	2	**Uphakamisa ibhodlela bese eziphuzela engasizwa muntu;** ***O phahamisa botlolo ka bo yena ho re a nwe*** Picks up bottle and drinks independently					
8	2	**Uyakuhlafuna ukudla okuqinileyo;** ***O hlafuna dijo tse tiileng*** Chews solid food					
9	2	**Udla ukudla okusikiwe kwaba yizicucwana/izigaxana/amadayisana;** ***O ja dijo tse kgabetsweng /sehiloeng*** Eats cut up/chunky/diced foods					

10	2	**Uyakukhotha ukudla okuzungeze umlomo;** ***O itatswa dijo tse leng molomonge*** Licks food from around mouth					
11	2	**Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe;** ***O ja di krakose, digwetwee kapa tseding tse bobebe*** Feeds crackers, carrot sticks or other finger foods					
12	2	**Uthatha isipuni esigcwaliswe ukudla asiyise emlonyeni;** ***O nka khaba e tletseng dijo ae kenye molomong*** Takes spoon filled with food to mouth					
13	5	**Uphuza ngenkomishi ngaphandle kosizo;** ***O nwa ho kopi ntle ho thuso*** Drinks from a cup without help					
14	5	**Uzidlela konke ukudla esebenzisa isipuni kanye;** ***O ja dijo kaofela a sebedisa khaba*** Feeds self entire meal using spoon					
15	5	**Uzithelela yena uqobo ingilazi noma inkomishi yejusi;** ***O itshella komiki ya juice yena ka byeena*** Pours himself or herself a glass or cup of juice					
16	5	**Usebenzia ummese khona "ezogcoba" ibhotela, ujamu njll;** ***O sebedisa thipa ho tlotsa jeme kapa botoro borothong*** Uses a knife for "spreading" butter, jam etc.					
17	5	**Usika ukudla okuthambile ngommese (ubhanana, izambane elibhakiweyo);** ***O seha dijo tse thapileng ka thipa (the ka dipanana, ditapole)*** Cuts soft foods with knife (banana, baked potato)					
18	5	**Usika inyama noma okunye ukudla kube izingcucwana ezizolumeka;** ***O seha nama, kapo dijo tse ding joalo-joalo*** Cuts meat or other food into bite-sized pieces					
19		**Uhluba ukudla oku-3 (ubhanana, inantshi, neqanda elibilisiweyo);** ***O ebolla dijo tse tharo (panana, mae a bidisitsweng)*** Peels 3 foods (banana, naartjie, boiled egg)					
		TOTAL EATING SCORE:				**/76**	

	Age of Indepen-dence (years)	**Functional mobility associated with Eating**	**1**	**2**	**3**	**4**	**Comments**
1	2	**Ufinyelela ebhodleleni noma enkomishini;** ***O fihlella botlolo kapa kopi*** Reaches for bottle or cup					
2	2	**Uphathe ipuleti elinokudla ngaphandle kokuchitha, waliyise etafuleni;** ***O phahamisa sejana se tletseng dijjo ntle le ho qhala tafoleng*** Carries a plate with food on it without spilling, to the table					
3	3	**Uyalugoqoza uketshezi ngesipuni;** ***O foduwaa metsi ka khaba*** Stirs liquid with a spoon					
4	3	**Ubuyisela isipuni endishini;** ***O khutlisetsa khaba sejaneng*** Returns spoon to bowl					
5	3	**Uyayiphakamisa futhi ayibuyisele inkomishi ihlale iqonde etafuleni;** ***O nka le ho khutlisetsa kopi tafoleng ka tsela e nepahetseng*** Picks up and replaces cup upright on the table					
6	5	**Uyazelula ukuze afinyelele eshalofini eliphezulu;** ***O ikotlolla ho nka ntho e hodimo shelefong*** Stretches to reach a high shelf					
7	5	**Uyasula lapho kuchitheke khona, azithathele indwangu yakhe;** ***O hlakola mo ho ghadiloeng teng, a late lesela ka boyena*** Cleans up spills, getting own cloth					
8	5	**Uphatha inkomishi egcwaliswe ujusi ngaphandle kokuchitheka;** ***O tsoara kopi e tletseng seno ntle le ho qhala*** Carries cup filled with juice without spilling					
9	5	**Uyalivula ibhokisi lobisi okanye lejusi;** ***O bula le bokoso la lebese kapa senwa maphodi*** Opens milk or juice box					
10	5	**Ulungisa isemeshi noma esinye isinekhi;** ***O itukisetsa sandwich kapa senekhe se seng*** Prepares sandwich or other snack					

		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH EATING SCORE:	**/40**	

	Age of Indepen-dence (years)	**Dressing**	1	2	3	4	**Comments**
1	2	**Uyazifaka izicathulo ezingafaswa;** ***O apara dieta tse sa bofuoang*** Puts on unfastened shoes					
2	2	**Uyazikhumula, impahla noma ijezi okuxegayo (impahla engena mkhono okokufasa);** ***O tlosa a T-shirt/ sikipa, mose kapa jerese e sa tlangoang*** Removes loose T-shirt skipper, dress or jersey (pullover garment without fasteners)					
3	3	**Uyazikhumula amasokisi kanye nezicathulo ezingafaswa;** ***O apola dikaosi le dieta tse sa tlangoang*** Removes socks and unfastened shoes					
4	3	**Uyazikhumula ibhulukwe elinelastiki okhalo;** ***O apola bodikhoe ba rekere thekeng*** Removes pants with elastic waist					
5	3	**Uyazikhumula ibhantshi uma lingafasiwe;** ***O apola jakete e sa tlangoang*** Takes off Jacket when unfastened					
6	3	**Asebenzise kahle okokokufasa ukungamavelikho;** ***O sebedisa hantle lebanta la velcro*** Manages velcro fasteners					
7	3	**Uyaziqaqa izintambo zezicathulo;** ***O bofolla dieta*** Unties shoes					
8	3	**Uyazigqokisa amasokisi;** ***O apara dikausu*** Puts on socks					
9	3	**Uyazigqokisa izicathulo onyaweni okuyilo;** ***O apara dieta leotong le nepahetseng*** Puts shoes on the correct feet					
10	3	**Uyazifasa izinkinobho abuye aziqaqe izinkinobho;** ***Oa bofa le ho bofolla dikonopi*** Buttons and unbuttons					

11	3	**Uyazigqokisa ibhulukwe , okuhlanganisa ukulifasa;** ***O apara bodikhoe le ho bofa teng mo*** Puts on pants, including fastening					
12	3	**Uyazikhumula ibhulukwe, elinga fasiwe;** ***O apola bodikhoe le ho ho bofolla*** Removes pants including unfastening					
13	3	**Uyazibopha izintambo zezicathulo;** ***O tlama di thapo tsa dieta*** Ties shoelaces					
14	5	**Uyazigqokisa isigqoko;** ***O apara katiba*** Puts on a hat					
15	5	**Uyazifasa abuye aqaqe uziphu, engasizwa;** ***O koala le ho bula zipu ka boyena*** Zips and unzips without help					
16	5	**Uyazigqokisa ibhulukwe elinelastiki okhalo;** ***O apara bodikhoe bo na leng rekere thekeng*** Puts on pants with elastic waist					
17	5	**Uyazigqokisa isikibha,ingubo noma ijezi okuxegayo;** ***O kapesa sekipa se bulehileng ka boeena mose kapa jerese*** Puts on loose T-shirt, dress or jersey					
18	5	**Uyazigqokisa futhi azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa;** ***O apara le ho hlobolaola sekipa se bulehileng ka pele, ntle le ho bofa dikonopi*** Puts on and removes a front opening shirt, not including fasteners					
19	5	**Uyazigqokisa amagilavu;** ***O apara di-gloves*** Puts on gloves					
20	5	**Uyazigqokisa noma azikhumule ihembe elivuleka ngaphambili, okuhlanganisa okokufasa;** ***O apara le ho tlosa hempe e bulwang ka pele*** Puts on and removes front opening shirt, including fasteners					
21	5	**Uyazibopha ibhande;** ***O bofa lebanta*** Buckles belt					

22	5	**Uyazigqokisa ibhande alifake emalupheni;** ***O apara lebanta a le kenye di-loopung*** Puts belt through belt loops					
23		**Uyalikhumula ibhande;** ***O tlamolla lebanta ka byeena*** Unbuckles belt					
		TOTAL DRESSING SCORE				**/92**	
		Functional Mobility Associated with Dressing	**1**	**2**	**3**	**4**	**Comments**
1	5	**Uyalibona ingemuva lezingubo;** ***Ua le bona lesela le ka morao*** Finds back of clothing					
2	5	**Uyazigoqa izingubo ezilula (izikipha, amahembe);** **O khona ho phutha diphahlo (t-shirt);** Folds simple clothing (T-Shirts, shirts)					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH DRESSING SCORE				**/8**	

	Age of Indepen-dence (years)	**Washing Items**	**1**	**2**	**3**	**4**	**Comments**
1	3	**Uyazesula ubuso bakhe uma enikezwe indwangu ngumuntu omdala;** ***U hlatso sefahleho ha a fuoe lesela*** Wipes own face when given a cloth by an adult					
2	3	**Uyazihlikihla izandla zombili khona ezozihlanza;** U sidila matsoho mmoho ho a hlwekisa Rubs hands together to clean					
3	3	**Uyazigeza izandla ngensipho;** ***U hlatsoa matsoha ka sesepe*** Washes hands with soap					

4	3	**Uyazigezisisa kahle izandla;** ***U hlatswisisa matsoho ha holo*** Washes hands thoroughly					
5	5	**Uyazesula izandla ngethawula;** ***U hlakola matsoho ka lesela*** Dries hands with towel					
6	5	**Uyazigeza ubuso cishe ngokwanele (kodwa hhayi ngemuva kwezindebe);** ***Ua hlatsoa sefahleho sa hae ka ho lekanela (le ha ese moraho ha ditsebe)*** Washes face more or less adequately (not necessarily behind ears)					
7	5	**Uyabomisa ubuso ngethawula;** ***U hlakola sefahleho ka lesela*** Dries face with a towel					
8	5	**Uyawugezisisa kahle umzimba, ungabuhlanganisi ubuso;** ***U hlatsoa mmele kaofela (ntle le sefahleho)*** Washes body thoroughly, not including face					
9		**Uyawomisisa kahle umzimba;** ***U hlakola mmele kaofela*** Dries body thoroughly					
10		**Uyazigeza umzimba wonke kahle engasizwa;** ***U hlapela waskomong ntle le thuso*** Washes using the basin without help					
		TOTAL WASHING SCORE:				**/40**	
		Functional Mobiliy Associated with Washing	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli ebhavini noma endishini;** ***Ua dula haeba a tshehetsehile setulong. sejaneng ke mohlokamedi;*** Sits if supported by equipment or caregiver in a tub or basin					
2	2	**Uyazihlalela engasekeliwe futhi anyakaze kubhavu;** ***UO dula ntle le tshehetso sejaneng, ntle le ho sisinyeha*** Sits unsupported and moves in the basin					
3	2	**Uyazilula izandla khona zizogezwa;**					

		Ho tsoara matsoho ho hlatsoua; Holds hands out to be washed					
4	2	**Uyazihlalela phansi abuye azisukumele ephakathi endishini;** ***Ua dula fatse le hoa ema hona ka hare sekotlolo*** Sits down and stands up from inside the basin					
5	2	**Uyazigibelela noma azishushuluzela ngezinqe engena noma ephuma kubhavu;** ***Ua palama kapa- o thella ka dibono ka hare le ka ntle ho sekotlolo;*** Climbs or slides on his or her bottom in and out of the basin					
6	3	**Uyazitholela insipho (kanye nendwangu yensipho, uma isetshenziswa);** ***U fumana sesepa kapa lesela ho di sebedisa;*** Obtains soap (and soaps washcloth, if used)					
7	5	**Uyazichithela amanzi endishini emuva kokugeza, ayihlanze endishi;** ***U tseba ho qhala metsi le ho hlakola basin ka mora ha ho hlapa;*** Empties basin after washing, clean the basin					
8	5	**Uyazithathela amanzi endishini ukuze ageze;** ***U tlatsa basin ka metsi hore a hlape;*** Fills up a basin with water for washing					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH WASHING SCORE:				***/32***	
	Age of Indepen-dence (years)	**Toileting Items**	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyakwenza adinga ukukwenza ethoyilethi engasizwa ngaphandle uma esedinga ukusulwa izinqe;** ***Ho finyella toilet ho hloka thuso beoue (ntle le thuso);*** Attends to toilet needs without help, except wiping					
2	3	**Uyalisebenzisa ipowa uma ebekwe kulo;** ***U sebedisa potty/chamber pot ha ba mmeile ho yona;*** Uses potty/chamber pot when placed on it					
3	5	**Ulisebenzisile iphepha eliwulwelwesi lasethoyilethi futhi waliphonsa ethoyilethi walishaya lahamba;**					

		U sebedisa pampiri ya ntloana ue lahlele ka ntloaneng; Uses the toilet paper and throws it into the toilet					
4	5	**Uyazinakekela uma esethoyilethi, azisule kahle futhi ageze nezandla;** ***U itlhokomela ka ntloaneng le ho itlhoekisa le ho hlatswa matsoho;*** Cares for himself at the toilet, cleans himself and washes hands					
5	5	**Uyalisebenzisa ithoyilethi ngaphandle kosizo;** ***U sebedisa ntloana ntle le thuso;*** Uses toilet without help					
		TOTAL TOILETING SCORE:				**/20**	
		Functional mobility associated with Toileting	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli;** ***Ua dula ha a thehiloe ke ntho kapa mohlokomedi;*** Sits if supported by equipment or caregiver					
2	2	**Uyakwazi ukuzihlalela abuye azisukumele labantu abadala;** ***Ua khona ho dula le ho theoha ntloana ya batho ba baholo;*** Gets on and off adult sized toilet					
3	3	**Uyazihlalela engasekeliwe noma esihlalweni esinepowa;** ***U dula hodimo ha potty a sa tsehetsoa;*** Sits unsupported on potty chair					
4	3	**Uyakwazi ukuzihlalela abuye azisukumele elifushane noma epoweni;** ***Ua palama a theohe potty ka boyena;*** Gets on and off potty					
5	3	**Uyakwazi ukuzihlalela abuye azisukele ethoyilethi, angadingi ukusebenzisa izingalo zakhe ukuze zimesekele uma ethwayiletile;** ***U palama le ho theoha ntloana/toilet a sa hloke matsoho ho motshehetsa;*** Gets on and off toilet, not needing his or her arms to support himself or herself on the toilet					
6	3	**Uya kwazi ukuzi thathela iphepha lasethwayelethi;**					

		U fumana pampiri ya ntloana; Gets toilet paper					
7	3	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** ***U khona ho fasolla/qaqha diaparo, le ho hulela madikhoe fathse;*** Manages to undo clothing fastenings, pulling down pants and underpants					
8	3	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** ***U khona ho apara hape madikhoe le mongato a be a bofe/tlamelle;*** Manages to pull pants and underpants back up and redo fastenings					
9	5	**Uyazisulisisa kahle emuva kokukaka;** ***U tseba ho e hlakodisa ka moraho ha e thusa ntloaneng;*** Wipes self thoroughly after bowel movements					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH TOILETING SCORE:				**/36**	

	Age of Indepen-dence (years)	**Grooming Items**	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyafinya ebanjelwe ulwelwesana lwephepha;** ***U khona ho hlakola nko, ha a tsoare tsoe pampiri/ uena ae tsoere;*** Blows nose into held tissue					
2	2	**Uyavuma ukusulwa amafinyila;** ***U dumela ho hlakoloa dinko tsa hae;*** Allows nose to be wiped					
3	2	**Uyazisula amafinyila esebenzisa ulwelwesana lwephepha uma eceliwe;** ***Ua hlakola dinko a sebedisa pampiri ha a kopioue;*** Wipes nose using tissue on request					

4	2	**Uyawuvula umlomo khona uzomxubha amazinyo;** ***U bula molomo hore a hlatsoe meno a hae;*** Opens mouth for teeth to be brushed					
5	3	**Uyaliqinisa ikhanda lime kahle ngesikhathi umkama izinwele;** ***U tseba ho tsoara hlooho ya hae hore a kamiwe moriri;*** Holds head in place while hair is combed					
6	3	**Uyazifinyisa futhi azisule amafinyila ngaphandle kokucelwa;** ***U tseba ho butsoetsa dinko le ho di hlakola ntle ho kopo;*** Blows and wipes nose without request					
7	5	**Uyazibhulasha noma azikame izinwele;** ***U tseba ho brusha kappa ho kama moriri*** Brushes or combs hair					
8		**Uyazigeza izinwele zakhe;** ***U tseba ho hlatsoa moriri oa hae***; Washes his or her own hair					
9		**Uyazixubhisisa kahle amazinyo;** ***U khona ho hlatswisisa meno;*** Thoroughly brushes teeth					
		TOTAL GROOMING SCORE:				**/36**	
		Functional Mobility Associated with Grooming	**1**	**2**	**3**	**4**	**Comments**
1	3	**Uyasibamba isixubho;** ***U khona ho tsoara brush ya meno*** **;** Holds toothbrush					
2	5	**Uyawufaka umuthi wokuxubha esixubheni;** ***U khona ho tlotsa brush ka toothpaste;*** Puts toothpaste on toothbrush					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH GROOMING SCORE:				**/8**	

		Functional Mobility Associated with Sleeping	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyaphakama ahlale embhedeni noma;** ***U khona ho phahama a dule hodimo ha bethe;*** Raises to a sitting position in bed					
2	3	**Alale phansi emuva kokuhlala osebeni lombhede;** ***U tseba ho paqama fatse morao ha hoba a dutse qetellong ya bethe;*** Lies down from sitting at the edge of bed					
3	5	**Uyazingenela futhi aziphumele embhedeni;** ***U tseba ho kena le hotsoa betheng;*** Gets in and out of bed					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH SLEEPING SCORE:				**/12**	

		General functional mobility Items	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyayinyakazisa into ayiyise emuva naphambili esebenzisa isandla esisodwa ayiyise kwesinye;** ***U khona ho tsamaisa ntho pele le morao ho tloha letsohong hoya ho le leng;*** Moves an object back and forth from one hand to another					
2	2	**Uyeluleka athathe izinto ngokugoba aye phambili;** ***U khona ho finyella ntho ka ho ea pele;*** Reaches for objects by leaning forward					
3	2	**Uyazicosha izinto phansi;** ***U khona ho phahamisa dintho tlase;*** Picks up things from the floor					
4	2	**Uyaziphatha izinto ezichobokayo noma ezichithekayo;**					

		U khona ho tshwara dintho tse thubehang kapa tse qhalanang; Carries fragile or spillable objects					
5	3	**Uyazihudula izinto phansi;** ***U khona ho tsamaisa dintho florong;*** Moves objects along the floor					
6	3	**Uyeluleka abambe into ebekwe eduzane;** **U khona ho finyella/tsoara ntho e beueng haufinyana;** Reaches out and grasps an object placed nearby					
7	3	**Ukuphatha izinto ezincane ngokwanele eziphatheka ngesandla esisodwa;** ***U khona ho tsoara dintho tse nyenyane tse khonang ho tshwareha ka letsoho le le leng.;*** Carries objects small enough to be held in one hand					
8	3	**Uyacokama ukuze afinyelele ezintweni;** **U khona ho ema ka menoana ya maoto ho finyella dintho;** Stands on tip toes to reach objects					
9		**Ukuphatha izinto ezinkulu ngokwanele ezidinga ukuphathwa ngezandla ezimbili;** ***U khona ho tsoara dintho tse kholo tsehlokang matsoho a le mabedi;*** Carries objects large enough to require two hands					
		TOTAL GENERAL FUNCTIONAL MOBILITY SCORE:				**/36**	

Scoring Form

Domain	Total Score	Percentage
Eating	/76	
Functional mobility associated with eating	/40	
Dressing	/92	
Functional mobility associated with dressing	/8	
Washing	/40	

Functional mobility associated with washing	/32	
Toileting	/20	
Functional mobility associated with toileting	/36	
Grooming	/36	
Functional mobility associated with grooming	/8	
Functional mobility associated with sleeping	/12	
General functional mobility items	/36	
Overall Total Point Score:	/436	

APPENDIX C ETHICAL CLEARANCE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Ms Caroline Seward

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M180954

NAME: (Principal Investigator)	Ms Caroline Seward
DEPARTMENT:	Occupational Therapy Tambo Memorial Hospital, Boksburg
PROJECT TITLE:	Selected psychometric properties of the Self-Care Inventory for Children with Celebral Palsy (SCICIP) for a low socio-economic South African context
DATE CONSIDERED:	28/09/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Denise Franzsen
APPROVED BY:	Dr C B Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	10/04/2019

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

DECLARATION OF INVESTIGATORS

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

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX D PERMISSION FROM THE CEO, THE HEAD OF PAEDIATRICS AND THE HEAD OF THE OCCUPATIONAL THERAPY DEPARTMENT AT TAMBO MEMORIAL HOSPITAL



Department of Occupational Therapy
Wits Education Campus

School of Therapeutic Sciences, Faculty of Health Sciences, 7 York Road, Parktown, 2193, South Africa
Tel: +27 11 717 3701 | Fax: +27 717 3709 | Email: leilane.bogoshi@wits.ac.za | **www.wits.ac.za**

Letter of permission to conduct research study at Tambo Memorial Hospital

Dear Dr. Naidoo

Title: Investigating selected psychometric properties of the Self-Care Inventory for Children with Cerebral Palsy for a low socio-economic South African context

I, Caroline Seward, a master's student in occupational therapy at the University of the Witwatersrand, am doing research on how children with cerebral palsy do activities to care for themselves like washing and dressing. This research will help therapists' plan therapy for these children. I would like to find out what each child's ability is to perform self-care tasks depending on their age, movement and hand function. In order to determine how well a child with cerebral palsy performs on the assessment, I need to test how typically developing children do these activities as well.

The assessment is called the Self- Care Inventory for children with Cerebral Palsy (SCICP). I would like to ask caregivers of children without any problems who attend your facility to fill in this assessment form. For this study, a total number of 50 children are needed to fill in this assessment form. I will have an information sheet translated into isiZulu and Sesotho for the caregivers telling them about the research, as well as consent forms that will be explained to the caregivers with the help of a research assistant who can speak Sesotho and isiZulu. This form takes approximately 45 minutes to fill in. I will also be there to assist caregivers, if they need help filling in the form.

Please will you grant me permission to ask caregivers of children attending your facility to fill in this assessment form?

Yours sincerely
Caroline Seward
072 597 0297

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

OFFICE OF THE CEO
Dr. A. Naidoo
Tambo Memorial Hospital
: (011) 898-8317
: (011) 892-0358
: AvisN@gpg.gov.za

MEMO

To : Ms Caroline Seward

From : Dr A Naidoo
Chief Executive Officer

Date : 20 January 2019

Subject : **Request to Carry Out Research at Tambo Memorial Hospital**

This serves to grant permission to Ms Caroline Seward to carry out a research study: *Selected psychometric properties of the self-care inventory of children with cerebral palsy (SCICIP) for a low socio-economic South African context* at Tambo Memorial Hospital. This permission is granted in light of improving the skill capacity of the Gauteng Department of Health.

The permission is granted in line with the code of ethics or research.

The information of the Gauteng Health Department will be used for the purpose of research and it will be utilized discreetly and confidentiality will be maintained at all times.

The permission is granted in good faith with the notion and understanding that the abovementioned clause is upheld.

Furthermore, there should be no financial implication to the hospital.

The collection of data will be the responsibility of the researcher.

Yours Sincerely,

.....
Dr A Naidoo
Chief Executive Officer

TAMBO MEMORIAL HOSPITAL
DR. A. NAIDOO
2019 -02- 20
CEO
GAUTENG PROVINCIAL GOVERNMENT

Letter of permission to conduct research study at the Occupational Therapy Department at Tambo Memorial Hospital

Dear Eunice Senwedi

Title: Investigating selected psychometric properties of the Self-Care Inventory for Children with Cerebral Palsy for a low socio-economic South African context

I, Caroline Seward, a master's student in occupational therapy at the University of the Witwatersrand, am doing research on how children with cerebral palsy do activities to care for themselves like washing and dressing. This research will help therapists' plan therapy for these children. I would like to find out what each child's ability is to perform self-care tasks depending on their age, movement and hand function. In order to determine how well a child with cerebral palsy performs on the assessment, I need to test how typically developing children do these activities as well.

The assessment is called the Self- Care Inventory for children with Cerebral Palsy (SCICP). I would like to ask caregivers of children without any problems who attend your facility to fill in this assessment form. For this study, a total number of 50 children are needed to fill in this assessment form. I will have an information sheet translated into isiZulu and Sesotho for the caregivers telling them about the research, as well as consent forms that will be explained to the caregivers with the help of a research assistant who can speak Sesotho and isiZulu. This form takes approximately 45 minutes to fill in. I will also be there to assist caregivers, if they need help filling in the form.

Please will you grant me permission to ask caregivers of children attending your facility to fill in this assessment form?

Yours sincerely

Caroline Seward
072 597 0297

PERMISSION TO COMPLETE RESEARCH

Title: Investigating selected psychometric properties of the Self-Care Inventory for Children with Cerebral Palsy for a low socio-economic South African context

I Eunice Senwedi (print name) hereby give permission for Caroline Seward to complete her research study at Tambo Memorial hospital at the Occupational Therapy department with mothers/caregivers of children with cerebral palsy who form part of the multidisciplinary CP clinic.

Signed: Senwedi

Date: 12/02/2019

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Department of Occupational Therapy
Wits Education Campus

Letter of permission to conduct research study at the paediatric outpatient department at Tambo Memorial Hospital

Dear Dr Mjamekwane

Title: Investigating selected psychometric properties of the Self-Care Inventory for Children with Cerebral Palsy for a low socio-economic South African context

I, Caroline Seward, a master's student in occupational therapy at the University of the Witwatersrand, am doing research on how children with cerebral palsy do activities to care for themselves like washing and dressing. This research will help therapists' plan therapy for these children. I would like to find out what each child's ability is to perform self-care tasks depending on their age, movement and hand function. In order to determine how well a child with cerebral palsy performs on the assessment, I need to test how typically developing children do these activities as well.

The assessment is called the Self- Care Inventory for children with Cerebral Palsy (SCICP). I would like to ask caregivers of children without any problems who attend your facility to fill in this assessment form. For this study, a total number of 50 children are needed to fill in this assessment form. I will have an information sheet translated into isiZulu and Sesotho for the caregivers telling them about the research, as well as consent forms that will be explained to the caregivers with the help of a research assistant who can speak Sesotho and isiZulu. This form takes approximately 45 minutes to fill in. I will also be there to assist caregivers, if they need help filling in the form.

Please will you grant me permission to ask caregivers of children attending your facility to fill in this assessment form?

Yours sincerely
Caroline Seward
072 597 0297

PERMISSION TO COMPLETE RESEARCH

Title: Investigating selected psychometric properties of the Self-Care Inventory for Children with Cerebral Palsy for a low socio-economic South African context

I Dr. Zukisum Mjamekwana (print name) hereby give permission for Caroline Seward to complete her research study at Tambo Memorial hospital at the Paediatric Outpatient department with mothers/caregivers of children who are typically developing according to their developmental milestones who attend doctor's appointments at the hospital.

Signed: .....

Date: 20/03/2018

APPENDIX E PERMISSION TO CONDUCT RESEARCH AT THELLE MOGOERANE REGIONAL HOSPITAL

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: O/M P.Moeketsi /P/N Mabizela
Directorate: Staff Development
Telephone number: (011) 590 0109
Email: Thandiwe.Mabizela @gauteng.gov.za

Date: 12 August 2019

Ms Caroline Seward

Thelle Mogoerane Regional Hospital Management Team is pleased to grant you provisional permission to conduct your study to conduct research **On selected psychometric properties of the Self-Care Inventory for Children with Celebral Palsy (SCICIP) for low socio-economic South African context at Thelle Mogoerane Regional Hospital.** Your data will be conducted through obtaining information through **"Prospective spective data collection"** in your protocol for which you will obtain the ethics clearance certificate from the University of Witwatersrand for Full permission to be granted.

The following condition must be adhered to otherwise permission will be withdrawn:

- Only the research and/or research methods outlined in the protocol presented to the Research Committee should be conducted and/or followed otherwise the research will be cancelled.

Please note that you can only get full clearance once you provide the hospital with the Ethics Clearance Certificate

Dr M.M. Malatji
Chief Executive Officer
Thelle Mogoerane Regional Hospital
Date: 15/8/2019

"To be the best provider of quality health care services to the people of Gauteng"

APPENDIX F PARTICIPANT INFORMATION SHEET

INFORMATION SHEET TO CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY/ TYPICALLY DEVELOPING CHILDREN

Study title: Investigating selected psychometric properties of the Self-Care Inventory for Children with Cerebral Palsy for a low socio-economic South African context

Hello, I, Caroline Seward, a master's student in occupational therapy at the University of the Witwatersrand, am doing research on how children with cerebral palsy do activities to care for themselves like washing and dressing. This research will help therapists' plan therapy for these children. I would like to find out what your child's ability is to perform self-care tasks depending on their age, movement and hand function.

Invitation to participate: I would like to invite you to take part in this study by completing the self-care questionnaire about your child. By completing the questionnaire, you will be giving me permission to use the results from the questionnaire about your child in my study. This will take about 25 minutes and someone will be there to assist you if you do not understand some of the questions. You will need to fill in a questionnaire, which asks you about how your child eats, dresses, washes and goes to the toilet. These questions will ask you how much help your child needs to complete the task. There are no directly related risks to being involved in the study and no direct benefit to you.

Participation in the study is voluntary. If you want to take part in the study you can, if you do not want to be part of the study, you do not have to do it. There will not be any penalty/ punishment to you if you do not want to take part in the study. You are allowed to stop participating in the study at any time.

Confidentiality: Your, and your child's, personal information that is shared during the research study will be kept confidential and no names will be collected. Organizations that may inspect my research records for quality assurance and data analysis include groups such as the Research Ethics Committee and the Medicines

Control Council. Should you have any queries or concerns you may contact me on 072 597 0297

Contact details for research and the HREC administrator and chair for reporting of complaints / problems add

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you

Caroline Seward

APPENDIX G INFORMED CONSENT FORM

WRITTEN CAREGIVER INFORMED CONSENT FORM

RESEARCH: Investigating selected psychometric properties of the Self-Care Inventory for Children with Cerebral Palsy for a low socio-economic South African Context

Date: _____

I, _____,

mother of_____ confirm that I have been told about the research in a language that I understand. I have also received, read and understood the written information regarding the study.

- I am aware that any information I give to the researcher will be kept private and all the results will be anonymously processed.
- I understand that at any stage, I may take myself and my child out of the study. I understand that if I decide not to take part, or I change my mind, nothing will happen to me or my child.
- I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily.
- I agree that my child and I will volunteer to take part in this study.

Caregiver's name: _____ (please print)

Caregiver's signature: _____

Interviewer's name: _____ (please print)

Interviewer's signature: _____

APPENDIX H WRITTEN CAREGIVER INFORMED CONSENT FORM FOR PHOTOGRAPHS/VIDEO

RESEARCH: Investigating selected psychometric properties of the Self-Care Inventory for Children with Cerebral Palsy for a low socio-economic South African context

Date: _____

I, _____,

caregiver of_____ give consent/do not give consent (circle appropriate response) for Caroline Seward to take photographs and/or videos for the purposes of her study.

I am aware that any information I give to the researcher will be kept private and all the results will be anonymously processed.

Caregiver's name: _____
(please print)
Caregiver's signature: _____

APPENDIX I VERBAL ASSENT FOR CHILDREN

“Hello, my name is Caroline. I would like to see how you take off your jacket, shoes and socks and see how you put them on again. Would you like to do this for me? You are allowed to say no if you don’t want to do it.”

APPENDIX J TURNITIN REPORT

PSYCHOMETRIC PROPERTIES OF THE SELF-CARE INVENTORY FOR CHILDREN WITH CEREBRAL PALSY IN A RESOURCE-CONSTRAINED URBAN SOUTH AFRICAN CONTEXT

ORIGINALITY REPORT

14%	8%	7%	11%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

MATCH ALL SOURCES (ONLY SELECTED SOURCE PRINTED)

1%

★ Christine Imms. "Diversity of participation in children with cerebral palsy", Developmental Medicine & Child Neurology, 05/2008

Publication

Exclude quotes	On	Exclude matches	Off
Exclude bibliography	On		

APPENDIX K PHOTOGRAPHS FROM OBSERVATION

Typical child






Children with cerebral palsy








**Please note that all of the children's faces have been blacked out for confidentiality reasons*