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THE FACTORS THAT INFLUENCE THE OCCUPATIONAL CHOICES OF HIGH FUNCTIONING LATE ADOLESCENTS (AGES 15-19) DIAGNOSED WITH CEREBRAL PALSY IN GAUTENG

Miksha Jagwanth

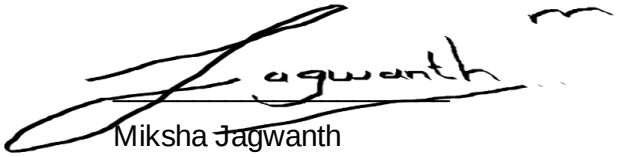


A research report submitted to the Faculty of Health Sciences, University of Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.

Johannesburg, 2021

DECLARATION

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



Miksha Jagwanth

6rd September 2021

DEDICATION

I dedicate this dissertation to the strong, independent ladies in my life.

First, I would like to dedicate this to my mother, my best friend, without your consistent support and love, this would not be possible.

Dad, my world and my sunshine. I miss you every time I breathe.

Grandma and Leela, for being my source of light and always making my dreams come true.
Anjana, for showing me what true strength looks like, and being my inspiration.
Barbara and Bugs, thank you for always being my constant cheerleaders. Shivam, and Rishav, thanks for the laughs.

To the 12 strong participants who opened their hearts and presented me with the knowledge that will aid other children and adolescents in similar situations. You have taught me that in life whatever comes your way can be endured and surpassed.

Last. But certainly not least. To my partner and best friend, Kreegan. You provided me with the encouragement that no one could ever give. Thank you for your patience, trust, and understanding. You have supported me in all my endeavours, and you pushed me when I wanted to give up. I know that I am truly blessed to have you in my life. Thank you for not giving up on me. I love you to the moon and back.

"We know what needs to be done and how to do it, as it is important to what we want to achieve.
What we are today is because of who we have been and who we want to become. We will continue to make it.
Our new story is open ended, the journey will open up new paths along our way.
It is a story of unfolding learning."

ABSTRACT

High functioning late adolescents with Cerebral Palsy (CP) face significant barriers to their occupational participation and performance in their occupational choices. Occupational choices and occupational participation are linked to general health and wellbeing, however late adolescents with CP are being overlooked. Previous research reveals that adolescents with disabilities have fallen through the cracks and are often forgotten in research studies.

The study aimed to explore the facilitators and barriers which impact on the occupational choices of high functioning late adolescents with CP within Gauteng, South Africa (SA). It has been found that minimal research has been conducted in SA surrounding this topic, with a paucity of information surrounding adolescents with disabilities within Gauteng.

Twelve (12) late adolescents (ages 15-19) with CP were selected through purposive sampling, using a preselected criterion relevant to the study's research questions. Schools were selected through convenience sampling within Gauteng, SA. Data collection occurred through semi-structured interviews based on the Occupational Performance History Interview (OPHI-II) as a primary data gathering tool.

MAXQDA, a computer data analysis programme was utilised incorporating thematic analysis for interpretation. Data analysis in the Qualitative Research process was followed for the analysis and interpretation of data.

Three themes emerged from this qualitative study. Theme 1 emerged as 'being included in their life's decisions and their occupational choices' which is related to the facilitator which influences the occupational participation and occupational choices of high functioning late adolescents with CP. Feeling not good enough (inferior) with associated family and community stigma as well as not feeling safe within their environments were two of the main barriers which impacted negatively on their occupational choices and occupational participation.

This study provided additional information surrounding decreased education of stakeholders, constant marginalisation and exclusion which are experienced by adolescents with disabilities in their communities within Gauteng, SA.

Future research is recommended especially in developing contexts, local and global partnerships with other researchers, therapists and members of the community whilst sharing their research

findings to increase the knowledge surrounding high functioning late adolescents with CP. This study focused on late adolescents with CP; further research is needed amongst this age category as well as expanding these ages so that barriers to meeting developmentally age-appropriate milestones throughout the years can be identified as well as predict barriers that may arise in meeting future milestones.

Society needs to work as a collective so that we can decrease these barriers to facilitate success in meeting these milestones appropriately, therefore providing the individual with an increased chance for success in life. International research should be culminated, and prototypes developed to decrease experienced barriers and increase facilitators that impact on the occupational choices and occupational participation of adolescents with CP. Integration of multidisciplinary approaches should be encouraged, especially within universities throughout SA and globally.

The significance of the study is that it will aid to the body of knowledge surrounding high functioning late adolescents with CP. The study hopes to help guide parents, families and healthcare practitioners to prepare high functioning adolescents with CP to cope with these life changes, meet their developmental milestones and to decrease the barriers that they face whilst progressing through this difficult period in their life. The facilitators should be used to improve and assist with increasing meaningful activity participation, to ensure that their occupational choices and occupational participation are positive.

Keywords: Adolescents with disabilities; Barriers; Brain Damage; Development; Cerebral Palsy; Disability; Gauteng; South Africa; Occupational therapy; Facilitators; Occupational performance; Occupational choices; Quality of life, Occupational Performance History Interview; (OPHI-II), Havighurst developmental needs.

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CONFLICT OF INTEREST

I hereby declare that there is no conflict of interest pertaining to this study.

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ACRONYMS AND ABBREVIATIONS

ADL's	: Activities of Daily living
AAC	: Argumentative and Alternative Communication
CDC	: Care Dependency Grant
CP	: Cerebral Palsy
DD	: Developmental Delay
GDE	: Gauteng Department of Education
GMFCS	: Gross motor function classification system
IADL's	: Instrumental Activities of Daily Living
ICF	: International Classification and Functioning
iPad	: A small portable computer activated by touching the screen
IQ	: Intelligence Quotient
LSEN	: Learners with Special Educational Needs
MAXQDA	: Software program for computer assisted qualitative data analysis
MACS	: Manual abilities classification system
MRI	: Magnetic Resonance imaging
OECD	: Organisation for Economic Co-operation and Development
OPHI-II	: Occupational Performance History Interview; version 2.1
OTASA	: Occupational Therapy Association of South Africa
P	: Participant
SA	: South Africa
SACPA	: South African Cerebral Palsy Association
StatsSA	: Statistics of South Africa
UNICEF	: United Nations International Children's Emergency Fund
QoL	: Quality of Life
WB	: World Bank
WHO	: World Health Organization
WIFI	: Wireless Fidelity
WMADoH	: World Medical Association Declaration of Helsin

CHAPTER 1

1. INTRODUCTION

1.1 INTRODUCTION TO THE STUDY

Cerebral Palsy (CP) is described as pervasive, non-progressive, and differs from person to person due to the vast differences in the type and distribution of the motor disorder. CP is explained as a group of disorders that impacts the development of motor ability, posture, movement, sensation, cognition, perception, communication and behaviour which in turn results in activity limitations in their valued occupations as well as their learning ability (Davis, Reddihough, Murphy, Epstein, Reid, Whitehouse, Williams, Leonard, & Dow, 2017; McIntyre, Morgan, Walker, & Novak, 2011; Ogoke, 2018; Pavone & Testa, 2015).

By the same token, McIntyre et. al., (2011) describes CP as "the most severe physical disability within the spectrum of developmental delay" (McIntyre et al., 2011, p. 47). Cerebral Palsy has been associated with comorbid conditions such as intellectual disability, sensory processing disorders, behavioural problems and epilepsy (Bax, Martin, Goldstein, Rosenbaum, Leviton, Paneth, Bernard, Jacobsson, & Damiano. 2005).

It is important to note the global prevalence rate of CP, as research indicates is between 0.2 and 0.33 % of the population equating to 2 to 2.5 births per every 1000 live births (The African Child Policy Forum, 2011; Pavone & Testa, 2015). At the same time, the statistics within South Africa (SA) have been noted to be underreported, impacting negatively on the reliability and credibility of the findings of many studies. Statistics within Africa have been reported as generally higher than the previously estimated global statistics as well as associated with more severe physical disabilities, due to the increased burden of infectious diseases and differences in prenatal and postnatal care available (Donald, Samia, Kakooza-Mwesige, & Bearden, 2014; Khandaker, Sheedy, Islam, Jung & Novak, 2015). South Africa's reported prevalence of CP is between 1% and 8% with the birth rate being every 10 per 1000 (The African Child Policy Forum, 2011).

There is value in researching CP within Gauteng, SA as it assists in providing accurate insights into CP and associated contextual facilitators and limitations in performing

occupations. Context-specific information is needed to initiate and develop integrated services whilst providing the best level of care available.

Authors from previous studies have identified the need for longer-term training programmes where both clinical and research collaborations are priority, increasing existing networks and decreasing isolated practice. Authors further found that information surrounding the prevalence and aetiology of CP within SA need to be identified and targeted effectively within a multi-disciplinary manner. There is a paucity of information surrounding the effects, occupational choices and occupational participation of individuals with CP within Gauteng, SA.

Consideration also needs to be given to the diagnosis and classifications of CP as this predicts functional outcomes. Accurate identification of CP is now possible before the age of six months, using Neonatal Magnetic Resonance Imaging (MRI), the Prechtl Qualitative Assessment of General Movements (GMs), and the Hammersmith Infant Neurological Examination (HINE). Important indicators at this age include delayed milestones such as head lags, inability to grasp, and/or hand asymmetry (Burger & Louw, 2009; Novak, Morgan, Adde, Blackman, Boyd & Brunstrom-Hernandez, 2017).

Now that we have looked at classifications and the diagnosis of CP, it is important to determine the severity of CP to assist with the prediction of their future and treatment planning (Novak et al., 2017). At the same time, it has been reported that accurate determination of the severity of CP is difficult due to the constant development of the brain and motor skills. The severity is only able to be reliably classified in children two years and older, using the Gross Motor Functional Classification Scale (GMFCS) and the Manual Ability Classification System (MACS) (Palisano, Rosenbaum, Walter, Russell, Wood, & Galuppi, 2008). Functionality depends on severity. The onset of spasticity is still largely under-researched, and the presence or absence of hypertonia has been noted to evolve (Novak et al., 2017).

Many individuals with CP will have numerous impairments which will have a negative impact on the status of their health, Quality of Life (QoL) for both the individual and the family, as well as increased costs to the family and society (McIntyre et al., 2011). Correspondingly, the severity and combination of symptoms due to CP differ from person to person. It has been reported that associated impairments include that one in three people with CP is unable to walk, one in four are unable to talk, one in ten have

a severe visual impairment, one in two have an intellectual impairment, and three in four experience pain (McIntyre et al., 2011).

An important trademark of CP is a disorder in the development of gross motor functioning, impacting negatively on occupational participation causing activity limitations throughout their lifespan (Rosenbaum et al., 2002). An equally significant aspect of CP, developmental delays and difficulties are a result of an impairment of the developing central nervous system (Rosenbaum et al., 2002). McIntyre et al., (2011) highlight that functional and associated impairments set CP apart from other milder disorders, these impairments increase with the severity of motor dysfunction (McIntyre et al., 2011). Himmellmann and Uvebrant's (2011) study participants expressed that the associated impairments often have a greater impact on functioning and QoL than their motor impairment solely (Himmelmann & Uvebrant, 2011).

Accordingly, the functioning of the individual with CP was assessed using the GMFCS and the MACS assessment. The GMFCS varies from level 1 (e.g. walking independently) to level V (needing to be transported in a wheelchair) (Compagnone et al., 2014).

The MACS assessment, on the other hand, varies from level 1 (handles objects successfully) to level V (handling of objects is severely limited) (Eliasson, Krumlinde-Sundholm, Rösblad, & Beckung, 2007). High functioning adolescents with CP have been classified as functioning within GMFCS levels 1, 2 and 3, as well as MACS levels 1, 2 and 3. The ability of the individual to understand and respond appropriately is also a focus when classifying the level of severity (Eliasson et al., 2007).

In addition to the GMFCS and the MACS, the assessment of performance in activities of daily living (ADLs), such as eating, dressing and play are also included to achieve a more holistic and occupational based view of the individual (Eliasson, Krumlinde-Sundholm, Rösblad, Beckung, Arner, Öhrvall, &; Rosenbaum, 2006; Morris, Kurinczuk, Fitzpatrick, & Rosenbaum, 2006; Palisano et al., 2008; Wood & Rosenbaum, 2000). High-level motor functioning, with associated cognitive functioning, have been related to an increased QoL, however the correlation for happiness and functioning is not as linear (Davis, Waters, Mackinnon, Reddihough, Graham, Mehmet-Radji, & Boyd, 2006).

Adolescents with pervasive disabilities struggle to meet their age-typical developmental tasks. When compared to their non-disabled peers, adolescents with disabilities such as CP, presented with more problems regarding the acceptance of their bodies, reaching autonomy, developing and maintaining romantic relationships, developing friendships, and developing socially responsible behaviour. Disabilities restrict opportunities to explore and participate in activities, which they want and need to perform (Pinquart & Pfeiffer, 2015).

1.1.1 Adolescents and CP

United Nations International Children's Emergency Fund (UNICEF) age band of late adolescence (15-19 years) was utilised (United Nations International Children's Emergency Fund, 2011). Development during adolescence prepares individuals for changes in their social roles such as getting married and having children. Cognitive development in late adolescence prepares individuals for independence in their futures, but research has found that independence and occupational choices are taken away from adolescents with disabilities (South African Human Rights Commission, 2018; Groce, 1999). Individuals with disabilities such as CP are often denied the right to build families on their own. "Social and family constraints make it unlikely that many young people with disabilities will marry" (Groce, 1999 p. 19).

Moreover, each life stage accompanies its own set of challenges, especially with a disability such as CP. Within SA, it has been noted that disabled children are less likely to attend school when compared to their non-disabled peers. This has a future impact on their literacy ability and the capability to gain meaningful employment in the future, leading to limited occupational opportunities (Kidd, Wapling, Bailey-Athias, & Tran, 2018). Vulnerability and social isolation were highlighted as important factors to take into consideration as challenges that individuals with CP currently face (Kidd et al., 2018).

Kidd et al., (2018) further highlighted challenges faced by individuals with disabilities across their lifecycle. Disability had a significant impact on the income and productivity in SA (Kidd et al., 2018). Within the household, individuals with disabilities are often placed at a higher risk of living within informal, traditional households with inadequate access to sanitation and water, including outside toilets and overcrowding (Kidd et al., 2018).

Occupational choices outlined by Rommes, Overbeek, Scholte, Engels, and De Kemp (2007) refer to the assessment of the match of own self-image and the occupations they consider participating in, shaped by personal and environmental factors (Galvaan, 2015; Rommes et al., 2007). Gallagher, Pettigrew, and Muldoon (2015) identified occupational choices to be a human right and have a strong link to wellbeing. In relation to adolescents with CP within Stewart et al.'s (2012) study found that there is a lack of occupational choices available to adolescents with disabilities (Stewart et al., 2012; Rommes, 2007). Marginalised disadvantaged adolescents with CP are considered to be at risk of occupational injustice (Gallagher, Pettigrew, & Muldoon (2015). Reasons stem from feeling different to their peers, levels of gross motor functioning, manual ability, cognition, communication skills, gender, level of communication and socio-economic backgrounds have been noted as both facilitators as well as barriers to participants experiencing connectedness to the performance of occupational activities (Rommes et al., 2007; Stewart et al., 2012).

The research surrounding this topic is pertinent however limited within the South African context, needing more relevant information to assist with policy planning, development, and evaluation of the success of these strategies. The information surrounding occupational choices within SA will assist with guidance and career counseling development, suggesting that occupational therapists must place social context as a priority to improve the well-being of marginalised individuals (Naidoo, 2000; Gallagher, Pettigrew & Muldoon, 2015).

The plight of adolescents with disabilities is not only desperate but also often overlooked, "they are among the neediest and most overlooked of all the world's children" (Groce, 1999 p. 2). Groce (1999), albeit an older study where findings of the study still prove to be true 21 years later, highlighting that a very small percentage of the millions of youths with disabilities (ages 10-24) have lives or will have futures as rich as their non-disabled peers, irrespective of their common needs and interests. Reasons for these barriers which have emerged through thematic results by Groce (1999) include aspects such as their lack of independence, bullying by peers, and impact of community stigma (Groce, 1999).

It is known that adolescents with disabilities are not just vulnerable but have also fallen through the cracks throughout the years of research and seeking appropriate health care (Groce, 1999). It is important to further research their choices and participation within occupations, and the facilitators and limitations experienced, especially within

SA, and locally in Gauteng so that we as parents, society, and health care practitioners may understand, empower and assist them to engage in meaningful occupations, meet their developmental life tasks, and therefore being able to experience life satisfaction.

1.2.1 Problem Statement

Research indicates that there is limited information and active participation within the occupational choices available to high functioning late adolescents diagnosed with CP within Gauteng, SA. This limited information and lack of active occupational choices and participation of high functioning late adolescents with CP within SA in the lives of their families, societies, and communities which often leads to isolation and are at a greater risk of depression and low self-esteem (Groce, 2004). Occupational participation and performance in occupational choices, which is often overlooked, is linked to general health and wellbeing and has been found to be limited within high functioning late adolescents with CP (American Occupational Therapy Association, 2014).

There is limited literature, especially within Gauteng, SA surrounding the facilitators and barriers, which influence the occupational choices of high functioning late adolescents with CP. These factors need to be fully understood to enable and facilitate high functioning late adolescents with CP to participate in activities of their choice and therefore improving their functionality, general health, and wellbeing.

1.2 PURPOSE OF THE STUDY

The purpose of the study is to explore the facilitators and barriers that impact the occupational choices of high functioning late adolescents with CP. It has been found that minimal research has been conducted in SA surrounding this topic, with a paucity of information surrounding adolescents with disabilities within Gauteng, SA. This study will attempt to fill the existing gaps in research.

The study hopes to help guide parents, families, and healthcare practitioners to prepare high functioning adolescents with CP, to cope with these life changes and decrease the barriers that they face whilst progressing through this difficult period in their life. The facilitators should be used to improve and assist with an increase in meaningful activity choice and participation, whilst ensuring that their occupational performance and priorities are positive.

1.3 RESEARCH QUESTION

What are the factors that influence the occupational choices of high functioning late adolescents diagnosed with CP?

1.4 AIM OF THE STUDY

The aim of the study is to explore the factors that impact the occupational choices of high functioning late adolescents with CP.

1.5 OBJECTIVES OF THE STUDY

- To explore the facilitators that impact the occupational choices of high functioning late adolescents with CP within Gauteng, SA.
- To explore the barriers that impact the occupational choices of high functioning late adolescents with CP within Gauteng, SA.

1.6 JUSTIFICATION FOR THE STUDY

It has been reported by the South African Human Rights Commission (2018) in their research brief on Disability and Equality in South Africa, that disabled people continue to be marginalised and excluded from being able to fully participate within society, experiencing occupational injustice (South African Human Rights Commission, 2018; Gallagher, Pettigrew & Muldoon, 2015).

The significance of the study is that it will aid the body of knowledge surrounding high functioning late adolescents with CP. The study hopes to help guide parents, families, and healthcare practitioners to prepare high functioning adolescents with CP, to cope with these life changes and decrease the barriers that they face whilst progressing through this difficult period in their life. The facilitators should be used to improve and assist with an increase in meaningful activity participation, to ensure that their occupational performance and priorities are positive.

Many studies have focused on either the effect of CP in childhood or within the adult age range. Information was needed during practice, specifically for late adolescents diagnosed with CP and their occupational participation profiles, especially due to the uniqueness of contextual factors within SA. Adolescents with CP within Gauteng, SA, need to be understood to enable occupational participation whilst partnering with these adolescents to be able to inform occupational therapy practice in more effective and efficient assessment and treatment.

1.7 PRESENTATION OF CHAPTERS IN THE DISSERTATION

Chapter 1 presents the outline of the background of the study, highlighting core research questions and aims. Chapter 2 focuses on the relevant literature, concentrating on current and contrasting research whilst identifying gaps within the available literature. Chapter 3 highlights the methodology, focusing on qualitative research through the use of thematic analysis. Chapter 4 describes and presents the findings of the study. Chapter 5 relays discussions surrounding the study's research findings and contributions to the body of knowledge. Lastly, recommendations for future research will be presented. High functioning late adolescents have been compared to their non-disabled peers throughout the study.

CHAPTER 2

2. LITERATURE REVIEW

2.1 INTRODUCTION

This chapter provides an overview of global research, literature, and knowledge surrounding the facilitators and barriers that impact the occupational choices of high function late adolescents with CP. This chapter further identifies, surveys, and synthesises previous international and local studies on adolescents with CP. The literature review assisted in scoping out key data collection requirements as well as assisting the researcher to give a formal review of the current study's perspective. This chapter reports on the description, causes, classification, functional classification, and impact of CP on the occupational performance within the different spheres of an adolescents' life. Activities of Daily Living and iADL's will be described and compared to their non-disabled peers. The importance of performance in these occupations, with a focus placed on the impact within SA, was reviewed and reported on, followed by the significance of acceptance of their disability by the individual, family members, peers, and other members of the community.

The search process for literature involved the databases PubMed/ MEDLINE, EBSCO Host, and Google Scholar. The articles were screened according to the title, abstract, and date, case studies were excluded. Inclusion criteria were applied to the abstracts and full text if the abstract was insufficient, including keywords surrounding cerebral palsy, occupational therapy, occupational participation, occupational choices, and performance of adolescents diagnosed with CP.

2.2 CEREBRAL PALSY

Cerebral Palsy has been classified as "the most severe physical disability within the spectrum of developmental delay" (McIntyre et al., 2011, p. 47). Cerebral Palsy has been outlined as a permanent disorder of muscle tone and movement, which impacts the ability to engage and participate in daily life (Bax et al., 2005).

2.2.1 Causes of Cerebral Palsy

Cerebral Palsy is caused through damage of the brain which can either be congenital (injury occurs during foetal development) or acquired, where the injury occurs before the age of two (Coombe, 2017).

The global prevalence of CP is between 0.2% and 0.33%, but in SA the prevalence is between 1% and 8% with the prevalence rate being every 10 per 1000 births (Donald et al., 2014). Birth trauma is one of the primary causes as the majority of South Africans live in a state of poverty and are unable to access adequate health services (Donald et al., 2014; Van der Merwe, 2017).

The aetiology of CP is divided into three periods: prenatal, perinatal and postnatal which is assessed and determined through physical examinations and neuroimaging (Ozdemir & Tezcan, 2017; Russman & Ashwal, 2004). The causes for CP depend on the period that the brain damage occurs, which assists to classify CP into prenatal, perinatal, and postnatal (Ozdemir & Tezcan, 2017).

The prenatal period is classified as the period before birth, encompassing the period from the formation of an embryo to the development of the foetus (Shikako-Thomas et al., 2013). Risk factors for CP during this stage include irregular cycles, maternal drug use, pre-eclampsia, strokes, infections, and placental abruption (Ozdemir & Tezcan, 2017; Russman & Ashwal, 2004).

The perinatal period is determined by the World Health Organization (WHO) from 22 weeks gestation to the first seven days of the infant's life (World Health Organization, 2013). Risk factors for CP during this period are associated with the length and induction of labour, maternal trauma, multiple pregnancies, birth asphyxia, and sentinel events such as cord prolapse with associated hypoxia of the foetus (Ozdemir & Tezcan, 2017; Russman & Ashwal, 2004).

The postnatal period is classified by WHO (2013) as the first six weeks after birth (World Health Organization, 2013). The risk factors for CP during this period include infections, injuries meningitis, septicemia, cerebrovascular accidents, malaria, and trauma (Ozdemir & Tezcan, 2017; World Health Organization, 2013).

Cerebral Palsy is not a progressive condition (Bax et al., 2005). However, if intervention is not adequate, loss of functioning can be progressive. In addition, the prognosis of the individual with CP depends on the type and classification of CP. Secondary complications and associated impairments include symptoms such as intellectual impairments with associated learning difficulties, impaired perception and sensation, communication difficulties, epilepsy, and behavioural problems contribute to the progressive loss of functioning (Bax et al., 2005; Rogers, 2010).

2.2.2 Classification of Cerebral Palsy

Many studies highlighted the challenges associated with the single-use classification of CP (Coombe, 2017; Ogoke, 2018). Multiple classification systems and assessments are currently being utilized. The use of a single classification system is considered incomplete due to the lack of a compressive and holistic assessment (Ogoke, 2018).

Individuals with CP differ clinically and important factors such as the age of the child, reliability, and extent of the diagnostic medical history of both the child and mother impact the clinical classification of CP (Bax et al., 2005; Ogoke, 2018). The different classifications are utilized to describe the nature of the disability, predicting the current and future needs of the individual, as well as assessing change after an intervention (Bax et al., 2005).

Different classification systems include physiological, topographic, and functional are utilized at different periods throughout life. The usage of which depends on associated changes in the individuals' condition such as age and growth and the expertise and qualifications of the treating healthcare professionals, location, and regions that the individual with CP has access to. Availability and affordability also impact the types of classifications that the healthcare professional has access to (Bax et al., 2005; Ogoke, 2018).

The WHO and the International Classification of Functioning (ICF) emphasized the importance of developing and focusing on the functional classification of the individual with CP. Using a functional classification of CP is preferred as it assists in guiding the management of the condition (Ogoke, 2018).

2.2.3 Functional Classification

The functional classification systems continue to be the best classification of CP. It classifies the levels of severity based on the functional (motor) abilities or limitations with performing activities (Pakula, Braun, & Yeargin-Allsopp, 2009; Shapiro, 2004). International advocacy and usage of functional assessments have been emphasized due to the important role these assessments play in the management of CP (Ogoke, 2018).

The below functional scales have been utilized to assess skills:

- Assessment of eating/drinking through the Eating and Drinking Ability Classification System (Sellers, Mandy, Pennington, Hankins, & Morris, 2014).

- Communication through the Communication Function Classification System (Hidecker et al., 2011)
- Gross Motor Function through the Gross Motor Classification System (GMFCS) (Palisano et al., 2008)
- Fine motor ability through the Manual Abilities Classification System (MACS) (Eliasson, Krumlinde-Sundholm, Rösblad & Beckung, 2007)

These systems assist with categorizing the severity of a limitation that the individual with CP experiences, rather than an actual assessment or outcome measure. The systems have been validated by many studies and have been found to be reliable and objective (Morris et al., 2006; Palisano et al., 2008; Wood & Rosenbaum, 2000).

These functional assessments advocate and follow the paradigm shift from the previous focus on the functioning of the body structure to an emphasis on activity participation, highlighting the interactive and constantly interlinking relationship between health condition and contextual factors, which is linked to occupational justice (Rosenbaum, 2003; Rosenbaum & Stewart, 2004).

The Manual Ability Classification System (MACS) developed by Eliasson et al., (2006) is designed for individuals with CP (Eliasson et al., 2006). The MACS classifies the way individuals with CP utilise their hands to manipulate and handle everyday objects in their home, school, and community environments. This includes assessment of performance in activities of daily living such as eating, dressing, and play (Eliasson et al., 2006).

Level 1 of the MACS describes the adolescent as being able to handle everyday objects easily and successfully especially when performing novel tasks within unfamiliar situations. The description includes when the only limitations are seen handling very small, heavy, or fragile objects. These limitations do not restrict independence in everyday activities (Eliasson et al., 2006).

Level 2 of the MACS describes that the adolescent with CP “handles most objects but with somewhat reduced quality and/or speed or achievement” (Eliasson et al., 2006 p.3). This level further defines that the adolescent can handle most objects, however, some activities are avoided or accomplished with some difficulty. Alternative ways of performance are sometimes utilised but do not usually restrict independence (Eliasson et al., 2006).

Level 3 of the MACS describes that the adolescent with CP handles objects with difficulty, relating to slow performance and limited quality success. Adaptation and modified activities assist independence within this level (Eliasson et al., 2006).

The Gross Motor Functioning Classification System (GMFCS) was initially designed and published by Palisano et al., (1997), later expanded by Palisano et al., (2007) to increase the assessed age range and include adolescents (Bax et al., 2005; Palisano et al., 2008).

The GMFCS is outlined as an ordinal scale, used to categorise and differentiate children and adolescents on their ability to perform a self-initiated movement, ambulatory patterns, and/or lower limb functioning in five levels. The scale ranges from level one (walking without restrictions and limitations) to level five (needing to be transported in a wheelchair) (Palisano et al., 2008). The GMFCS is further used to assist with the prediction of equipment the child may need in the future, such as wheelchairs and crutches (Palisano et al., 2008). The GMFCS assists with determining the severity level of the individual through the use of an objective classification of the individual's motor disability, the higher the level in GMFCS, the more severe the CP (Compagnone et al., 2014).

Classification of children with CP is based on their functional abilities, (GMFCS) and the Manual Ability Classification System (MACS). The MACS assessment, on the other hand, is designed to classify how individuals with CP use their hands and handle everyday objects, the focus is on their manual ability. The lower the level of MACS, the more severe the CP (Compagnone et al., 2014).

The advantages of using both the GMFCS and MACS classification systems include the assistance and focus on families and healthcare workers to provide appropriate care to the individual’s functional level and allowing continuous evaluation of the effectiveness of treatment throughout development (Bax et al., 2005; Palisano et al., 2008; Rosenbaum, 2003; Rosenbaum et al., 2007; Wood & Rosenbaum, 2000).

Iloeje and Ogoke (2017) found a positive association with the type of CP, the number of accompanying impairments, and the severity of gross motor dysfunction and walking ability amongst individuals with CP (Iloeje & Ogoke, 2017). The classification system of both the GMFCS and MACS further assists with helping occupational therapists and the healthcare team discuss and set realistic rehabilitation goals and plan for current

and future services needed by the individual with CP (Rosenbaum, 2003). The researchers' view on the value towards the GMFCS, and MACS is positive based on the therapists' past experiences of success and qualitative evaluation of initial functionality when compared to during or after therapy, whilst taking the environment into account to fully assess performance in occupations.

2.2.4 Impact of Cerebral Palsy

The severity and combination of symptoms due to CP differ from person to person. It has been reported that one in three people with CP are unable to walk, one in four are unable to talk, one in ten have a severe visual impairment, one in two have an intellectual impairment, and three in four experience pain (McIntyre et al., 2011).

Global research indicates that although personal and physical environmental factors continue to be a limitation to participation for an individual with a disability, the perceptions of the people around them emerge as playing a big role on the impact of their occupational performance in everyday activities and full participation in society (Groce, 1999; Law, Petrenchik, King, & Hurley, 2007; Shields & Synnot, 2016). This decreased participation often leads to social isolation and it has been found that adolescents with CP are more likely to be depressed and present with low self-esteem (Espín-Tello, Dickinson, Jiménez-Bernadó & Caballero-Navarro, 2018).

Limitations, prejudices, and stigma placed upon them when combined with their unmet needs continue to be the most prevalent barrier in the participation of adolescents with disabilities in the lives of their families, societies, and communities (Groce, 1999).

Robert Havighurst (1948) proposed a series of developmental tasks which an adolescent needs to progress through to achieve life satisfaction and approval from society, which in turn increases the adolescents' Quality of Life (QoL). The series of developmental tasks originated in 1930, further developed in the 1940s, and put into practice during the 1950s. If these tasks are not met, it is theorized that difficulties with further tasks throughout their lives are experienced (Havighurst, 1948; Manning, 2002).

Havighurst (1972) study proposes the following developmental tasks (Havighurst, 1972):

1. *Achieving new and more mature relations with age-mates of both sexes:* This involves learning to look at boys and see men, and girls to women. This task also includes learning to work together with a common goal in mind.

2. *Accepting one's physique and using the body effectively:* This involves acceptance and leading a healthy life through aspects such as proper nutrition, exercise, and prevention of communicable diseases.
3. *Achieving emotional independence from parents and other adults:* This involves developing affection and respect for parents and older adults, without dependence upon them.
4. *Preparing for marriage and family life:* This involves acquiring knowledge and making decisions towards family life, marriage, and having children.
5. *Preparing for an economic career:* This involves developing and achieving goals set by the individual regarding their future career and vocational goals. The individual needs to decide how they are going to make a living.
6. *Acquiring a set of values and an ethical system as a guide for behaviour*: This involves participating as a responsible and ethical person within all aspects of the individual's life.
7. *Desiring and achieving socially responsible behaviour:* This involves the adolescent behaving responsibly and taking on the responsibilities that are required by society.

A study conducted by Schleyer-Lindenmann (2006) found that the contextual differences between countries suggest that the developmental tasks are not identical within different cultures, therefore this needs to be taken into consideration during data collection and analysis within SA (Schleyer-Lindenmann, 2006).

It has been found that adolescents with disabilities struggle to meet their age-typical developmental tasks. When compared to their non-disabled peers, they had more problems with regards to acceptance of their bodies, reaching autonomy, developing and maintaining romantic relationships and friendships, and developing socially responsible behaviour amongst others as their disability restricts their opportunities to explore (Pinquart & Pfeiffer, 2015).

Stewart et al., (2012) reported on numerous factors that were brought up by adolescents with CP affecting their social participation in their society. All participants in Stewart et al., study brought up the importance of socialisation, which included both direct face-to-face contact as well as communication with their friends using technology and social media (Stewart et al., 2012). This directly influences Havighurst's (1972) developmental task of achieving and maintaining mature relationships and impacts on the adolescent achieving socially responsible behaviour (Havighurst (1972).

There has been limited research in the development of adolescents with CP in reference to Havighurst's (1972) developmental tasks, especially within SA. Difficulty in meeting age-appropriate developmental tasks is common in adolescents with CP due to associated impairments, community stigma, perception of self, lack of knowledge surrounding appropriate behaviour, and lack of experience regarding appropriate social skills, often leading to behavioural difficulties (Havighurst, 1972). Brossard-Racine and Majnemer (2013) highlighted those behavioural difficulties are likely to emerge between the ages of six to twelve and not likely to diminish throughout maturity (Brossard-Racine & Majnemer; 2013). It has been noted that there is an additional burden which disability places on adolescents as they meet the demands of the required tasks. Achievement of developmental tasks is important for the development of personal independence and their own philosophy in life, this is linked with preparation for the success of the performance of occupation (Havighurst, 1972).

2.2.1 FOCUS ON CONTEXT WITHIN SOUTH AFRICA

South Africa has been described as a country of diversity however Levin (2006) and Baratt and Penn (2009) reported that the majority of South Africans living with a disability experience challenges exacerbated by poverty and access, linked with the burden of other diseases and restricted choices. There is no known nationally or locally organized body that assists with the interests of disabled students within SA, to collaborate on their needs. Within higher education, Levin (2005) states that SA lacks the resources needed to provide structure and establish formal registration to indicate the incidence of CP within the country (Levin, 2005; Matshedisho, 2007).

Socioeconomic factors should be considered when seeking factors, which contribute towards an increased exposure and health care access for CP in SA. Poverty places neonates at a significant disadvantage, which may result in CP. Within SA, many communities and pregnant mothers do not have access to running water and live-in unsanitary conditions (Levin, 2006).

SA has unique traditions and healers, which are not often seen in other parts of the world. It is researched that at least 80 percent of the South African population seek the services of traditional healers (Levin, 2006). Many seek help from both traditional and western healers. It is thought that healers focus on restoring both the physical symptoms and the spiritual world of the person, whereas western medication focuses on correcting the disorder and is considered the separation of the mind and the body (Levin, 2006).

Many families within SA are affected by HIV/AIDS, where mothers have died and the child with CP often receives kinship care from relatives, clans, and tribes. HIV/AIDS further exacerbates the burden of care of children with CP, leading to the disempowerment of the family, especially being unemployed, illiterate, or uneducated.

The cohesiveness of the families was affected by the atrocities of the apartheid. Breadwinners had to leave their homes to find employment in urban areas, separating the family. Specialised education was focused on 'white' children, and the language of teaching and learning was conducted in Afrikaans and further took on a Christianity dominance. The first school to be established for 'black' children with disabilities within SA, opened within Soweto, Johannesburg, Gauteng. The training and facilities within this school were said to be inadequate, and very few children with disabilities were able to access specialised schools, mainstream schools were unable to meet the demands of the individuals with disabilities (Levin, 2006).

2.3 CATEGORIES OF OCCUPATION AND OCCUPATIONAL CHOICES

The term occupation has been broken down into eight categories, namely: Activities of Daily Living (ADL's), Instrumental Activities of Daily Living (iADL's), education, leisure, play, rest and sleep, social participation, and work (American Occupational Therapy Association, 2014). On the other hand, it has been found that adolescents with disabilities that need extra support have decreased occupational choices both within and outside of school. Research has found that disabled learners have not been given the same educational and recreational opportunities, feeling marginalized and excluded within their environments (Shah, 2005). These concepts will be outlined in subsection 2.3 below.

2.3.1 Activities of Daily Living

Activities of daily living (ADL) are described as activities which an individual participates in to take care of their own body such as bathing, dressing, functional mobility, feeding grooming, hygiene, personal device care, swallowing/eating, and toileting (American Occupational Therapy Association, 2014; Shikako-Thomas et al., 2013).

Milnac and Feng (2016) suggested that an individual's performance of ADL tasks is dependent on their cognitive ability, such as planning and reasoning, adequate motor ability, such as dexterity and balance, and perception and sensory abilities (Mlinac & Feng, 2016). Emotional and behavioural factors, such as a lack of motivation due to

depression must also be considered to ensure a holistic view, as these could potentially pose as a barrier to independence (Mlinac & Feng, 2016).

Dependence on others for assistance with ADL's has been associated with decreased QoL, impacting on an increase in institutionalisation as well as an increased risk for mortality due to the associated risks with a lack of participation and isolation due to dependence impacting on meeting Havighurst's (1972) developmental stages appropriately (Havighurst, 1972; Broe et al., 1998; Millán-Calenti et al., 2010; Ramos, Simoes & Albert, 2001).

2.3.2 Instrumental Activities of Daily Living

The Instrumental Activities of Daily Living Scale has been identified by Lawson and Brody (1969) as being a person's ability to use a telephone, do shopping, perform household tasks and do their laundry. It also refers to their ability to use transportation, administer their medication, and handle their finances (Lawton & Brody, 1969).

Walking independently has been identified by numerous studies as one of the main precursors for success in performance in iADL's within individuals with CP. As the GMFCS levels decrease, so do the rates for successful participation in iADL's. Promoting gross motor functioning may have a positive increase in independent participation in iADL's (Bjornson, Zhou, Stevenson, & Christakis, 2014; Pashmdarfard & Amini, 2017). These studies were not conducted and applied within SA.

Within a Global North context, Van der Dussen et al., (2001) found that despite the high level of independence in performing iADL's, adolescents with CP are poorly integrated within the community, schools, and in sports (Van der Dussen, Nieuwstraten, Roebroeck, & Stam, 2001). These were supported by a past study conducted by Lepage, Noreau, Bernard, and Fougeyrollas (1998) who found disrupted performance of adolescents with CP when performing recreational, educational, and community integration activities (Lepage, Noreau, Bernard & Fougeyrollas, 1998).

2.4 EDUCATION AND SCHOOLING

Education includes formal and informal educational needs and participation (American Occupational Therapy Association, 2014).

A study focusing on the teacher's perceptions of catering for learners with disabilities revealed that teachers felt better prepared to include the more severe forms of CP, as they felt that the needs of these learners are 'obvious' when compared to mild CP learners, where teachers struggled to identify the impact of the disability on the child, therefore, making it difficult for teachers to determine the appropriate level of support (Tindal, 2017).

A research participant with mild CP reflected on his schooling experience and felt that his needs were often neglected because teachers struggled to identify the smaller things, he needed assistance with throughout the day, forcing him to do things that due to his disability, unable to perform which lead to traumatic experiences and embarrassment (Tindal, 2017).

Barriers to attending mainstream schooling include a poor adaptation of the school curriculum therefore limited academic learning, decreased funding and physical accessibility as well as insufficient teacher training. Limited school resources, personal barriers for accessing professional support as well as harassment and bullying from members of the community and peers have been noted as barriers (Jigyel, Miller, Mavropoulou, & Berman, 2018; The Victorian Equal Opportunity & Human Rights Commission, 2012). Further research is needed within SA surrounding how parents from different communities, cultures, and language varieties choose education programmes for their children with disabilities, focusing on inclusion, physical accessibility, teacher training, and adaptation of the school curriculum so that optimum learning and functionality is achieved (Mawene & Bal, 2018).

A study conducted in the Western Cape, SA found similar barriers to the attendance of school for adolescents with CP. Participants and parents of children with CP expressed that there were limited schools, which were equipped to care for individuals with disabilities. Often, more harm came from attendance of these schools, such as constant bedsores from being seated the entire day. Participants further described that the adequate schools were often too far away, or transport refused to assist due to the poor quality of the roads leading to residential homes (Pretorius & Steadman, 2018).

Past studies have shown attitudinal barriers and hesitation of parents towards sending their children with physical disabilities to a school (Jigyel et al., 2018; Leyser & Kirk, 2004; Shikako-Thomas et al., 2013). Schools seldom acknowledge the much-needed expertise of parents, teachers, and a multi-disciplinary inclusive practice to ensure success at school (Denman, 2014). Mawene and Bal (2018) found that parental choice for a school for their child with a disability is influenced by the areas that they have access to, socioeconomic status, race, and income (Mawene & Bal, 2018). It is however unwise to generalize ideas about the needs of parents and individuals with disabilities as they are not the same, the range of disabilities and associated impairments are vastly different (Taub, 2006).

Individuals, both with and without disabilities value their active participation at school as well as the social inclusion into the community, which formal schooling enhances (Curtin & Clarke, 2005; Denman, 2014). Barriers such as their unmet needs and lack of resources to support children with physical disabilities have a huge impact on their ability to reach their full potential (Imms et al., 2016). A successful inclusive schooling experience has been described as being involved in both curricular and extracurricular activities and events within the school environment (Singal, 2008).

Skill development often starts and occurs at school, which can either be a facilitator or a barrier to an individual with a disability. Skills such as social and motor skills are often learnt learned through practice, through the exposure of early opportunities present at schools (Shields & Synnot, 2016). Individuals with disabilities have been noted to have fewer opportunities for activities to master skills outside of the school situations. Reasons stem from being physically excluded from community programmes as well as parents' lack of enrolment of their child (Shields & Synnot, 2016).

Participants involved in Pretorius and Steadman's (2018) study view school as a facilitator. Four participants involved in the study noted that their child had progressed due to the activities and exercises, which they were actively participating in whilst at school. Another caregiver noted that the school, which her child was attending, had been a huge assistance to her, as she was issued exercises, which improved her child's speech and language ability (Pretorius & Steadman, 2018).

2.5 LEISURE

Leisure involves exploring and participating in various forms of leisure activities. It can further be described as activities we choose to do in our free time, often for enjoyment (American Occupational Therapy Association, 2014; Majnemer, Shikako-Thomas, Schmitz, Shevell & Lach, 2015). Participation in leisure activities has been noted to influence the perception of self, self-esteem, promote emotional and social skills, and may contribute towards happiness and enjoyment. Participation in chosen and preferred activities promotes overall well-being and QoL (Shikako-Thomas & Majnemer, 2012).

Shikako-Thomas et al., (2013) who explored leisure activities within adolescents with CP found that they participate in a variety of social and recreational leisure activities, however, they tend to avoid activities that demand skill-based and active-physical dexterity. Adolescents were more likely to participate in leisure activities, which are considered informal, and home-based (Shikako-Thomas et al., 2013). Adolescents with CP have been found to spend more time in isolated activities such as watching TV and using the computer (Aitchison, 2003; Shikako-Thomas et al., 2013). Leisure has been recognized as a human right, however, adolescents with disabilities are presented with fewer and less diverse leisure opportunities and occupational choices, when compared to their non-disabled peers (Shikako-Thomas et al., 2013).

Factors which are associated with prediction and participation in leisure activities have been related to the individuals' functional abilities, attitudes, socioeconomic status, contextual factors such as family and school environments, family activity-orientation, and parent educational level (King et al., 2003; Law et al., 2006; Shikako-Thomas et al., 2013).

A female-focused pilot study conducted by Toscos, Faber, Connelly, and Upoma (2008) found that technology, such as cell phones may provide scaffolding that encourages leisure, physical activity, and socialisation, however lack of reciprocity from the other party proves as a barrier to socialisation (Toscos, Faber, Connelly & Upoma, 2008). A study conducted by Nonis (2015) found that the participants' choice of devices and applications included smartphones, laptops, tablets, and computers. Applications utilised included WhatsApp and Twitter. Reasons for participation included assistance in establishing friendships, expansion of their social networks, and using social media as a platform for emotional support (Nonis, 2015).

Computer-based technology has been considered to be a facilitator as it allows the individual with CP to access a variety of activities of their choice (Chantry & Dunford, 2010). Participants explained that they felt it was easier to access, navigate and use their smartphones to access social media. The length of time spent on social media correlated with responding and commenting on current information about their online friends (Chantry & Dunford, 2010).

A study based in Singapore highlighted the limited information available on the use of technology for leisure purposes, this is seen within SA. It is important to note that barriers including mobile carrier charges as well as limited finger and hand dexterity could impede the usage of technology. Confidence and self-esteem have been reported as a pertinent factor for participation as it has been reported as needed to ensure successful communication to experience success (Nonis, 2015).

Shikako-Thomas et al., (2013) found a positive correlation between engagement in physical activities and psychosocial well-being, especially within individuals with CP. They further concluded that children and adolescents with disabilities who participate in physical activities positively support the development of ADL and iADL's skills (Shikako-Thomas et al., 2013).

Individuals with CP who participate in leisure activities have been found to generally feel better about their social interactions, functioning within a school as well as dealing with their emotions in a more positive manner. Shikako-Thomas et al., (2013) study concluded that adolescents with CP enjoyed participating in a variety of activities however their participation was limited as they tend to participate in activities that encourage social isolation (Shikako-Thomas et al., 2013). A decrease in participation correlates negatively with decreased functionality. This study however was based on both parent and child questionnaires and conducted within a Global North country (Shikako-Thomas et al., 2013).

Adolescents with CP from Shields and Synnot's (2016) study explained that sport is a big part of their lives and is often related to 'fun' and enjoyment, which is important in an individuals' life. Schools for learners with special needs have been identified to be a good source of information surrounding programmes and available sports (Shields & Synnot, 2016). Parents of children with disabilities expressed concern for their child's safety and at times, doubt their child's ability, therefore making the pivotal decision to exclude them from physical activities (Shields & Synnot, 2016).

Shields and Synnot's (2016) study found that parents of children with physical disabilities felt that it was difficult for their children to participate in physical activities that they want to do. Parents further felt that the child's age played a role in their participation, as they get older, the skill gap between the child with a disability and their non-disabled peer widens and sports become more competitive (Shields & Synnot, 2016). Parents felt that during this period, exclusion by their peers and teasing increased, leading to a lack of motivation by the child with a disability and therefore self-isolation (Shields & Synnot, 2016).

Melbøe and Ytterhus (2017) study found that disabled adolescents and their non-disabled peers exhibit similar preferences for leisure activities where both the groups preferred sports and cultural activities. Learners with disabilities have been found to participate less in leisure activities, and the frequency of participation decreases with age. Disabled adolescents further experience marginalisation within organized leisure activities (Melbøe, & Ytterhus, 2017).

Adolescents with CP value their ability to choose activities that they want and need to perform, as well as a choice surrounding their interaction with peers and friends. As researchers and advocates for individuals with disabilities need to encourage further research within the sphere of leisure and adolescents with CP within SA, to assist us in identifying the different leisure patterns, contextual factors, and barriers associated within SA.

2.6 PLAY

Play involves participating and exploring various forms of play activities, which is often performed for pleasure (American Occupational Therapy Association, 2014). Play is most commonly associated with the childhood age band and is considered a vital part of development (Guitard, Ferland, & Dutil, 2005).

Playfulness is a topic seldom studied in adolescents and adults, however, has had many benefits such as: alleviating boredom, assisting with releasing tension, improving group cohesion, and improving overall work quality and performance (Fine, 1987; Glynn & Webster, 1993).

Playfulness, when applied to adults, can be described as a “state of mind” (Guitard et al., 2005, p.12) which can assist with developing an individual’s ability to deal with frustration, anxiety, and deception. Playfulness is correlated with an individual’s adaptability. Playfulness has been reported to enhance an individual’s occupational performance (Guitard et al., 2005).

A study surrounding play in adolescents with CP, conducted by Shikako-Thomas et al., (2013) found that the adolescents participate in informal rather than formal planned play activities. Watching television, listening to music, and renting a movie were the most frequent informal activities performed daily as opposed to formal play activities. Formal play often involves physical activity involving active muscular functions, often having a positive impact on improving occupational components and therefore physical and cognitive ability, interconnected throughout the cognitive functioning of the person, environment, and occupations (Shikako-Thomas et al., 2013).

A study conducted within SA, interviewing siblings of individuals with CP found that siblings struggled to include the individual with CP into play activities. They further expressed feeling sadness for their sibling and wishing that they were not so restricted and able to play and participate in activities together (Mophosho, Widdows, & Gomez, 2009).

2.7 REST AND SLEEP

Rest and sleep refer to rest, sleep preparation and sleep participation (American Occupational Therapy Association, 2014). Sleep has been described by Heraghty, Hilliard, Henderson, and Fleming (2008) as imperative to overall wellbeing and health, learning, memory, and neurophysiologic functioning (Heraghty, et al., 2008).

Dutt, Roduta-Roberts, and Brown (2015) found in their study that 23% - 46% of children diagnosed with CP experience sleep difficulties. Predisposition stems from difficulties in cognition, sensory and motor abilities, such as immobility, seizures, and pain (Dutt, Roduta-Roberts, & Brown, 2015). Difficulties experienced in individuals with CP regarding rest, sleep preparation and participation has a negative effect on the individual’s emotions, cognitive, physical development, and general performance and in turn, impact on their QoL (Jan, 2006; Magee, Caputi & Iverson, 2012).

In research, deficits within sleep have been to interfere with an individual’s mental and physical well-being. Effects of sleep difficulties and deprivation can be seen in a

decreased mood, cognitive impairments, depression, decreased school performance as well as behaviour problems, such as aggression (Jan, 2006; Magee et al., 2012).

Caregivers may experience a further exacerbation of the caregiving burden which is placed on both primary caregivers and family members. They may experience sleep deprivation due to the constant interruption in their sleep cycles (Jan, 2006; Magee et al., 2012). This constant interruption can be due to the need for constant monitoring needed by the individual with CP (Wayte, McCaughey, Holley, Annaz, & Hill, 2012). The increase in caregiver burden and lack of sleep has been found to cause depression and other health issues in caregivers and families. The negative results of impacted sleep on the individual with CP have been noted to be extensive and holistic (Jan, 2006).

2.8 WORK

Work is important to an individual transitioning from school to a work environment. Work relates to employment interests and pursuits, job performance, preparing for retirement, and volunteer participation (American Occupational Therapy, 2014). Work contributes to the productivity of an individual, whether paid or unpaid is often associated with a sense of personal achievement, identity, and purpose.

Receiving an early diagnosis and therefore appropriate services from multiple medical, allied health and early intervention services is essential to participation within this sphere of life. Access to these services assists the individual to prepare for associated life challenges such as school and eventually transitioning to a work environment (Bourke-Taylor, Cotter, Johnson & Lalor, 2018).

Zhang and Stecker (2001) found that with intellectually disabled students, the continuous experiences of failure in performing tasks impacts negatively on their self-determination, efficiency, and self-esteem. This failure impacts the ability and self-esteem to set meaningful goals for their future impacting their self-determination (Zhang & Stecker, 2001). Wetherston, Karrim, and Pahl (2018) describe the importance of employment as it is a form of independence, self-acceptance and is important for improving their QoL. This correlates with Havighurst's (1972) developmental stages appropriately (Wetherston et al., 2018; Havighurst, 1972).

The findings from Wetherston et al., (2018) study conducted within SA indicate barriers within an individual with CP's difficulties with education, skill development, physical

accessibility, transportation, and limited job opportunities (Wetherston, et al., 2018). Individuals with CP who experience mobility restrictions often present with reduced educational achievements and therefore associated difficulties with involvement in paid work (Bourke-Taylor et al., 2018; Whetherston et al., 2018).

2.9 OCCUPATIONAL PERFORMANCE

Occupational therapy has been described as the achievement of health and well-being whilst being able to participate in life through engagement in occupation. According to the Occupational Therapy Practice Framework, the term 'occupation' has been defined as various daily activities in which an individual participates and engages (American Occupational Therapy Association, 2014). These occupations are central to a person's identity and their sense of competence in their abilities. The engagement of meaningful occupations maintains, promotes, supports, and facilitates an individual's health and wellbeing, improving QoL (American Occupational Therapy Association, 2014).

Quality of life encompasses overall health and wellbeing and is influenced by an individual's context, culture, and value system which relates to the goals, standards, and expectations of an individual (Chulliyil, Diwan, Sheth, & Vyas, 2014; Orley, 1996).

The developing population in SA found a paucity of information surrounding the QoL of people with disabilities when compared to their non-disabled peers. Performance of occupations is assumed to be affected by chronic conditions and impairments, in turn affecting their occupational performance in activities which the population with disabilities want and need to participate in, impacting negatively on their QoL and their closely related standard of living. Finkenflugel (2009) reported that people with disabilities were more likely to experience ill health, poverty, fewer opportunities to attend school and to find employment, and were often excluded socially, economically, and psychologically (Finkenflugel, 2009; Graham & Ross, 2016).

2.10 PERSONAL INDEPENDENCE

Cerebral Palsy is known to cause difficulties with movement and posture impacting the individual's ability to perform activities independently, at an acceptable quality, and with the desired outcome. Functional impairments evolve and change as the child develops, along with their need and want to perform their ADL's independently, and at an acceptable quality (Chulliyil et al., 2014).

Cerebral Palsy negatively impacts the child's independence significantly, and in turn, impacts on the QoL for the individuals' caregivers and family members (Chulliyil et al., 2014). The severity of the impairment correlates with the degree of impairment resulting in an increase or decrease of QoL. The study further suggests that increased independence by the individual with CP impacts positively on the individual, as they feel happier and better about their social and community interactions, functioning at school, and managing their emotions. This is however according to a parent report and not self-declared by the individual with CP (Chulliyil et al., 2014).

Adolescents with CP expressed their need and want to be in control of their own lives. Independent decision-making was mentioned by the majority of the participants as they began to look to the future and realized the importance of being able to make their own decisions (Stewart et al., 2012). This factor directly impacts Havighurst's (1972) developmental task of making decisions about marriage and family life, and self-sufficiency (Havighurst, 1972).

Davis, Shelly, Waters, Boyd, Cook and Davern (2006) found fifteen factors that contribute towards the QoL for adolescents with CP. These factors reported directly by adolescents with CP have included aspects of health, functioning, pain and discomfort, social wellbeing and acceptance within the community, participation in activities and being able to try new things, independence and transitioning into adulthood, emotional wellbeing, acceptance of disability and their limitations, access and a supportive physical environment, access to services, performing well at school, adequate financial resources, relationship and sexuality, communication and their parents' health (Davis et al., 2006).

The following pertinent themes were identified by Davis et al., (2017):

- Physical health and physical changes that occur during development.
  - Aspects included the changes n body size and physical health are important quantifiers of QoL. Adolescents who have decreased functioning often find performance within ADL tasks more difficult. Size and weight can affect mobility and balance.
- General functioning within all aspects of their life (including their limitations)
  - Functioning and quality of life are seen to influence each other.
- Pain and discomfort that adolescents with CP may find difficult to control.
  - A large percentage of adolescents with CP experience pain. Pain and quality of life influence each other.

- Social well-being and acceptance within the community and society
  - The maintenance of good relationships with both friends and family has been noted to play a major role in QoL. A participant from Davis et al., (2017) study explained that she felt that coping in life is dependent on support, as they push you to do better and perform better at tasks and occupations.
- Participation in activities and being able to try new things (including adaptations for the disability).
  - Adjustments may be required to facilitate participation and decrease limitations experienced. Participants from Davis et al., study (2017) expressed that they felt that their self-esteem is a barrier to their participation in their occupational choices. Adolescents with CP need to have the confidence to try new things and be able to adapt the activity to their own needs is important.
  - Independence and transitioning into adulthood (such as leaving home and finding a partner)
  - Gaining and maintaining independence is seen as central to QoL often hindered by their physical impairments.
- Emotional well-being and self-esteem.
  - Cerebral Palsy can often have a negative impact on the adolescents' wellbeing and self-esteem, which can result in frustration and anger. Feeling good about oneself increases QoL.
- Acceptance of their disability and limitations
  - Accepting ones' disability is seen as central to an adolescents' QoL.
- Access to a supportive physical environment and equipment
  - The importance of access and participation within their physical environment has been linked with QoL. An example being a well-designed house, equipment such as a wheelchair, assistive devices, and splints are important to facilitate participation and allow the adolescent with CP to move around his/her environment.
- Performing well at school
  - Being able to participate and enjoy all aspects of school has been reported to be important to an adolescent's QoL.
- Access to services
  - The importance of being able to access services is a pertinent factor to an adolescents' QoL. Parents reported that there has been a shortage of services available to adolescents with CP.
- Having adequate financial resources.

- Financial resources were brought up as being pertinent to the QoL of an adolescent with CP. Finances are important to afford therapists, medical interventions and equipment, to facilitate independence and functionality.

- Relationships and sexuality.
  - It is important for an adolescent to establish and maintain relationships with the opposite sex as well as being comfortable with their sexuality.
- Communication.
  - An adolescent with CP who cannot communicate with others can often feel frustrated and not heard. Being able to understand and be understood contributes to an adolescent with CP's QoL.
- Parent's health.
  - A dependent adolescent with CP's QoL often depends on their parents' health as the adolescent needs physical assistance.

Development during adolescence prepares for changes in social roles, getting married, and having children, therefore it is important to progress through these stages to assist with success in the future (Havighurst, 1972). Cognitive development in late adolescence focuses on preparation for independence, but research has found that this independence is taken away from adolescents with CP (Groce, 1999). Adolescents with disabilities are often denied the right to progress through these stages appropriately, such as being able to build families on their own, impacting on life satisfaction and therefore QoL. Research indicates that social and family constraints make it unlikely that many young people with disabilities will marry, as opposed to their non-disabled peers (Groce, 1999).

Soyupek et al., (2010) found that GMFCS level is an important predictor of an individual's QoL (Soyupek, Aktepe, Savas, & Askin, 2010). QoL can be improved by assisting the individual with CP to maximize functional independence, which can be aided through the use of assistive devices (Chulliyil et al., 2014).

Pretorius and Steadman (2018) who conducted their study within SA, Western Cape identifying facilitators and barriers experienced by individuals with CP. There is however a paucity of information surrounding the barriers and facilitators which high functioning late adolescents with CP experience within Gauteng, SA (Pretorius & Steadman, 2018).

2.11 ENVIRONMENT AND TRANSPORTATION

Transportation was one of the main barriers mentioned in Stewart et al., (2012) study, as the participants expressed that they are unable to be “spontaneous and carefree” in their decision making and social participation (Stewart et al., 2012, p.6). Participants in wheelchairs mentioned that they have to plan ahead and make arrangements for special transportation (Stewart et al., 2012). This impacts Havighurst’s (1972) developmental task of self-sufficiency as they are dependent on others for transportation (Havighurst, 1972; Stewart et al., 2012).

Pretorius and Steadman (2018) found that environmental conditions continued to be mentioned as a barrier to children with disabilities in terms of participating in the community (Pretorius & Steadman, 2018). A participant from the study explained that they are unable to access certain facilities within the community, due to the location of their homes and poor quality of roads, making it difficult to access main roads to participate within the society independently (Pretorius & Steadman, 2018). This further impacts the independence of the adolescent with a disability (Havighurst, 1972; Pretorius & Steadman, 2018).

Almost all the participants in Pretorius and Steadman's (2018) study utilised either public transport or walking to commute around the community. Participants expressed that the cost of taking the individual with a disability around is often very expensive and tiring for all parties involved. Public transport, such as buses and taxis do not cater for individuals who utilize a ‘buggy’, a large support wheelchair, as their mode of transportation, which often forces caregivers to push the buggy to their destination regardless of the distance (North, 2019; Pretorius & Steadman, 2018). This once again impacts the adolescent with a disability's ability to achieve independence due to their dependence on transport (North, 2019; Pretorius & Steadman, 2018).

Unsanitary living conditions associated with ill health were barriers also identified by many participants within the study. A participant expressed concern regarding their child with CP’s constant ill-health due to the unsanitary living conditions, negatively impacting their ability to participate within the society therefore further excluding the individual with CP from society and negatively impacting the development of social skills (Pretorius & Steadman, 2018).

Most of the participants in the Stewart et al., (2012) study expressed that the physical and social environmental limitations continue to be barriers to their social participation,

accessibility of buildings, and attitudes towards people with disabilities were mentioned (Stewart et al., 2012). These barriers correspond with a study conducted within SA, describing the poor conditions of the roads in the communities in which they reside, which does not always accommodate vehicles impacting on transport services accessing their homes, thus increasing social isolation (Stewart et al., 2012). The study further identified long distances in which a caregiver, as well as the individual with CP, need to travel to access health care services, attend follow up appointments as well as the decreased reliability and increased costs for transport, impacting on the financial burden placed upon caregivers (Pretorius & Steadman, 2018).

It has been found globally that not only the personal and physical environmental limitations of the adolescent with a disability but also the perceptions of the people around them impact adolescents with CP occupational performance in everyday activities and full participation in society (South African Human Rights Commission, 2018; Groce, 1999). These limitations often lead to social isolation and have been found that adolescents with disabilities are more likely to be depressed and have low self-esteem (Suris, Michaud, & Viner, 2004; South African Human Rights Commission, 2018; Groce, 1999).

These conditions identified the need for skilled facilitators and instructors who are equipped with adequate knowledge to assist the adolescent with CP to participate in activities of their choice, in the absence of exclusion and embarrassment (Conchar, Bantjes, Swartz, & Derman, 2016). These barriers directly influence Havighurst's (1972) developmental task of becoming self-sufficient, as the environment prevents the adolescent with CP from being independent in society and limits their social interactions (Havighurst, 1972).

Limitations, prejudices, and stigma placed upon them when combined with their unmet needs continue to be the most prevalent barrier in the participation of adolescents with disabilities in the lives of their families, societies, and communities (Groce, 1999; Groce, 2004; Pretorius & Steadman, 2018).

2.12 SOCIAL PARTICIPATION

Social participation is when an individual participates in community and family-based activities involving peers, family, or friends. Social participation has been described as being involved in a social situation with others and can be divided into face-to-face

interactions, or through technology such as a phone call or applications such as WhatsApp (American Occupational Therapy Association, 2014).

Facilitators towards an individual with CP's social participation were personal factors such as having a social personality and having the confidence to try out new things. Environmental facilitators such as assistive devices and accessible buildings were also noted in Pretorius and Steadmans' (2018) study. These facilitators have a positive impact on the achievement of Havighurst's (1972) developmental task of sufficiency and indirectly influence preparation for a job and career (Havighurst, 1972).

Shikako-Thomas et al., (2013) found in their study that participants who attended special segregated schooling were more likely to participate in social activities due to the adaptations made for their needs (Shikako-Thomas et al., 2013).

Adolescents with disabilities experienced decreased participation in physical activities (Shields & Synnot, 2016). A link has been found between participation in physical activities and promoting social engagement (Carlon, Taylor, Dodd, & Shields, 2013; Frey, Stanish, & Temple, 2008). Socialisation skills, which are built off socialisation in spheres such as leisure and socio-economic status have had a significant influence on the diversity and of active-physical activities (Shikako-Thomas et al., 2013).

2.13 PERSONAL SATISFACTION AND SOCIAL PARTICIPATION

Social participation assists with improving and contributing to successful participation in activities as skills are learnt through opportunity and practice (Anderson, Bedini, & Moreland, 2005; Shields & Synnot, 2016).

Social participation plays an important role in the maintenance of health and wellbeing. It has been described as a prerequisite for typical development as children often learn from each other and develop social skills during their interaction (direct or indirect contact) with others at home, in the neighbourhood, community, and school (American Occupational Therapy Association, 2014; Sahoo, Rege, & Rao, 2017). These environments can either facilitate or constrain an individual's participation, especially in the presence of a disability such as CP (Sahoo et al., 2017). Social participation prepares individuals for smooth transitioning from their home environments, to school and finally out into the community (Law, 2002; Sahoo et al., 2017).

Sahoo et al., (2017) study correlated individuals with higher levels of motor impairment with decreased social participation. Social participation was noted to decrease in the

home situation. This was explained by Sahoo et al., (2017) as an “overprotectiveness” from parents of the individual with a disability, parents feel guilty for their child’s disability and therefore perform their activities for them, limiting the experience of independent participation (Sahoo et al., 2017 p. 3).

Within the school environment, it has been found that learners with disabilities get continuous attention from teachers and school assistants, including during unstructured activities such as lunch breaks. Adult involvement in the school context has been found to limit social participation with peers (Richardson, 2002; Sahoo et al., 2017). Individuals with CP participate less within their school environment when compared to their non-disabled peers (Parkes, McCullough & Madden, 2010; Sahoo et al., 2017).

Bourke-Taylor's (2018) study emphasized the importance of inclusion and increasing participation in learning, cultures, and communities, therefore, eliminating exclusion (Bourke-Taylor et al., 2018). All participants in the study expressed that both the family and student valued friendships which corresponded with success and feeling a sense of belonging, decreasing exclusion (Bourke-Taylor et al., 2018).

2.14 PERCEPTIONS THAT IMPACT ON THE OCCUPATIONAL CHOICES OF HIGH FUNCTIONING LATE ADOLESCENTS WITH CEREBRAL PALSY.

The perceptions surrounding an individual’s disability from family, peers, and community members have been noted to impact the occupational choices and participation of high functioning late adolescents with CP.

2.14.1 Perceptions of Family

A study conducted in Iran found that the barriers experienced by individuals with CP, as reported by their families were external, such as the availability of transportation and availability of education (Nobakht, Rassafiani, Rezasoltani, Sahaf, & Yazdani, 2013). Financial strain, stigmatisation from others, lack of information surrounding their child’s diagnosis and opportunities as well as a lack of access to services continue to be barriers to participation in occupational choices of adolescents with CP (Davis et al., 2010; Donald et al., 2014; Pretorius & Steadman, 2018; Thrush & Hyder, 2014).

Finkelstein (2001) analysed the types of disabilities that belonged to self-help organizations for people with disabilities and found that people with CP were absent from these associations (Finkelstein, 2001). He further described that he felt that they

were often ‘overprotected’ by their ‘caring parents’ and therefore inactive and isolated. They were described as ‘passive’ with the perception that abled-bodied people will always look after them and their needs (Finkelstein, 2001).

Shields and Synnot (2016) highlighted that participants in their study felt that their families played an integral role in their participation in activities. Families are often needed to provide transport, assist with finding suitable activities, and most importantly, offering encouragement during these activities (Shields & Synnot, 2016). Participants described that they often relied on their parents to be proactive in researching appropriate and available activities being offered, advocating for their child to be included as well as appropriate modifications to facilitate participation (Shields & Synnot, 2016). A child with a disability is therefore disadvantaged if the families of the child lacked experience in the ‘how to’ and financial means to get their child involved (Shields & Synnot, 2016).

The authors highlighted that parents described that their children are often rejected in their cultures due to beliefs such as that the individual with a disability is cursed and bewitched. The birth of a child with a disability has been associated with the practice of witchcraft whereas others believe that their child is a punishment from their ancestors (Pretorius & Steadman, 2018). There is a paucity of information surrounding perceptions of families within Gauteng, SA.

Parents and family members are crucial to the participation of individuals with disabilities. The values that both the parents and the individual with disability place on participation are both interlinked and related. Shields and Synnot (2016) study found that the majority of parents are happy for their child to be active as they understand the potential benefits of their participation, however, their main difficulty to overcome is being able to balance the needs of all the family members (Shields & Synnot, 2016).

The relationship that a child has with their family has been found to create a bond of love and comprehension, which enables the communication between the two parties (Baltor, Borges, & Dupas, 2014). It has been reported in Baltor et al., (2014) study that the communication from a child with CP, extends further than the meaning of words, as the family often understands the meaning of the child’s feelings through gestures and expressions (Baltor et al., 2014).

Stigma due to the lack of coherent speech and motor difficulties associated with CP, often makes it difficult for the family and the society to hold a relationship. This lack of sensitivity towards the individual with a disability often impacts the entire family unit (Baltor et al., 2014).

2.15 FAMILY FINANCES

"It comes down to affordability" (Shields & Synnot, 2016 p. 4). Parents felt that there is an extra expense that accompanies caring for a child with a disability. Parents further explained that there is an increased need for one-on-one attention, which limits the time available to earn an income (Shields & Synnot, 2016).

Pretorius and Steadman's (2018) highlighted the financial burden of having a child with a disability. Many participants considered caregiving 'a full-time obligation', as they are unable to secure a stable occupation, which offers flexibility (Pretorius & Steadman, 2018). Majority of the participants involved in the study depend on the Care Dependency Grant (CDG) offered by the government.

A CDG is a programme, which has been implemented by the South African government to realise and give effect to the rights of people with disabilities. The CDG is used to ensure that every child has the right to basic shelter, nutrition, basic health care services, and social services. Children with disabilities are more likely to require extra care, support, and/or supervision while performing ADL's. In addition, medication, therapy, assistive devices, and regular hospital visits have been associated with increased costs of caring for a child with a disability (Martin, Proudlock, & Berry, 2014). Access to modified equipment, flexible payment options, and subsidised programmes are strategies that were identified to facilitate participation (Shields & Synnot, 2016).

2.16 COMMUNITY STIGMA

Finkelstein (2001) referred to disabled individuals as being 'socially dead' and further described that the disabled people of the world are 'virtually invisible' in the media such as in newspapers, television, and magazines (Finkelstein, 2001). "The rule, after all, is surely to hide disabled people away!" (Finkelstein, 2001, p.5). Social and environmental barriers prevent disabled people from being able to play an active role in societies, communities, and government (Finkelstein, 2001).

Barriers stemming from negative societal attitudes of disabilities were identified by Shields and Synnot (2016). Participants further highlighted that there is a lack of

knowledge, experience, and fear to include individuals with disabilities in activities, often viewing participation of people with disabilities as a low priority (Shields & Synnot, 2016).

Parents of participants felt that parents of non-disabled peers were often openly negative about socialising their non-disabled child with a disabled child. Parents blamed 'bad habits' that the non-disabled peer exhibits on the child with a disability. Parents of non-disabled peers do not allow socialization with the individual with a disability, exacerbating exclusion and opportunities to play (Shields & Synnot, 2016).

Pretorius and Steadman's study (2018) focused their study within the Western Cape, SA highlighted the community perceptions towards individuals with disabilities. These perceptions often lead to the child with a disability being rejected by community and family members. A participant within Pretorius and Steadman's (2018) study reflected on her mother (child's grandmother) rejecting the child with CP (Pretorius & Steadman, 2018).

Pretorius and Steadman's study (2018) highlighted the negative attitudes when the caregiver and individual with CP participate in public events. Participants reflected on their experience of others staring and touching their child which made them feel uncomfortable (Pretorius & Steadman, 2018). Other participants from the study reported teasing and laughing from the public, leading parents to feel anger towards community members. As a result, parents attempt to protect their children from ridicule and therefore purposefully socially isolating them further (Pretorius & Steadman, 2018).

Social exclusion is an old, known fact that is still present in society today. Individuals with disabilities are often seen as targets for biased attitudes and often, insensitive actions. Their rights as citizens are often disrespected as community members usually focus their attention on the individuals' disabilities, difficulties, limitations, and appearances rather than their capabilities and skills (Baltor et al., 2014; Palisano et al., 2010).

2.17 BULLYING

Bullying has been defined through a seminal source as 'aggressive behaviour used to repeatedly harm and intimidate others with less power' (Vaughn et al., 2010). The act of bullying occurs around peers and can be both direct behaviours towards an individual, such as verbal, physical, or written aggression, or indirect acts such as social

exclusion and written, electronic or verbal rumours which are harmful (Gladden, 2014). The victim is unable to defend themselves against a bully, which could be the reason for children and adolescents with disabilities being viewed as an easy target (Gladden, 2014; Jackson, Vaughn, & Kremer, 2019).

Adolescents with CP is categorized as a 'developmental disability' along with chronic conditions, have been found to be at a greater risk for bullying when compared to their typically developing peers as found by a study performed within the United States (Blake, Lund, Zhou, Kwok, & Benz, 2012; Jackson et al., 2019; Wood et al., 2005).

Lyndsay and McPherson's (2012) study found that bullying is an international problem with a high prevalence of verbal and physical bullying, among adolescents with CP (Lindsay & McPherson, 2012). This study focused on their experiences within the school environment. Individuals with CP, who are bullied have been found to experience negative mental, physical and social consequences resulting in difficulties in social competence, academics, behavioural difficulties, and general unhappiness at school (Lunde, Frisén, & Hwang, 2006; Roberts & Smith, 1999). Adolescents with CP have been noted to have fewer friendships and have been observed to experience peer rejection which prevents the formation of friendships (Jindal-Snape, 2004; Kent, 2003).

Within SA, studies have found that adolescents with CP prefer not to be watched, stared at, or made fun of when they move (Lindsay & McPherson, 2012). A participant from Lindsay's (2012) study reflected on her experiences of being laughed at when participating in physical activities within the school, she feels that she does not like being observed and would rather hide in a corner than be exposed to the bullying and staring whilst participating within the school environment (Lindsay & McPherson, 2012). Participants from the study describe the constant bullying experienced associated with being called 'cripple' which makes the adolescent with a disability feel worthless, questioning the reasons for being born into the world (Lindsay & McPherson, 2012).

Many studies throughout the years have sought to prove the link between being a victim of bullying and a variety of mental and behavioural health problems including depression and decreased self-esteem. This further exacerbates the exclusion of individuals with disabilities, impacting on their ability and confidence to make friends, communicate appropriately and to build social skills, and learn from their peers (Arseneault, Bowes, & Shakoor, 2010; Sentenac et al., 2012; Turner, Exum, Brame, & Holt, 2013; Valdebenito, Ttofi, & Eisner, 2015).

2.18 NEED FOR ACCEPTANCE AND INCLUSION

Shields and Synnot (2016) found that their research participants with CP described happy participation in activities when the activity is being enjoyed and is considered fun. This contributes to giving them a sense of accomplishment and competence as well as opportunities for socialisation. Occupational activities allowed them to engage with their peers and make new friends (Shields & Synnot, 2016).

Inclusion has been described as a universal human right, irrespective of race, gender, or disability. It involves eliminating discrimination whilst encouraging a sense of belonging, feeling respected and valued for who you are so that the individual can participate fully in occupations that they want and need to do. McKinney and Amosun (2020) suggested that we shift our thinking about disabilities being 'special' to being seen as 'normal' (McKinney & Amosun, 2020).

On one hand, a study conducted by Yssel et al., (2007) undertaken in both SA and the United States of America found that parents generally support the inclusion of their child with a disability, noting the positive effects which are associated with inclusion, such as promoting acceptance within their community as well as the development of social and emotional skills. This was however contrasted to the actuality of the situation where parents found that they experienced a lack of expertise in implementing inclusion strategies (Duhaney & Salend, 2000).

While on the other hand, within SA, Yssel et al., noted that the majority of the parents of children with disabilities are not adequately informed of the surrounding school and disability acceptance. Many schools have a reluctance or refusal to accept their child into the school. This was further described as a "painful journey" as parents have to "knock on doors and see which one is open" (Yssel, Engelbrecht, Oswald, Eloff, & Swart, 2007, p. 5).

Peer involvement and acceptance were once again brought up as strong motivators for participation (Shields & Synnot, 2016). Disability awareness programmes have been researched to positively change attitudes to increase understanding and tolerance to individuals with disabilities (Shields & Synnot, 2016).

Disability awareness programmes will also assist to minimize misunderstandings surrounding the needs and abilities of individuals with disabilities, therefore minimising

the stigma associated with a disability. This will have a positive impact on the occupational choices and occupational participation of adolescents with CP (Anderson et al., 2005; Shields & Synnot, 2016; Stuart, Lieberman, & Hand, 2006).

2.19 CONCLUSION TO THE LITERATURE REVIEW

The plight of adolescents with disabilities is not only desperate but also often overlooked, “they are among the neediest and most overlooked of all the world’s children” (Groce, 1999, p. 1) this quote was repeated due to the extremely powerful weight that it carries, as seen throughout literature. Only a small percentage of the millions of children with disabilities (ages 10-24) have lives or will have futures as rich as their non-disabled peers, irrespective of their common needs.

It is well known that adolescents with disabilities are not just vulnerable, but have also been forgotten throughout the years, we see this in the literature review as pertinent information which affects the factors which influence occupational participation and occupational choices of the adolescent with CP (Groce, 1999).

It is important to further research facilitators and limitations that high functioning adolescents with CP are experiencing, especially in SA, and locally in Gauteng so that we, as parents, society, and health care practitioners may empower adolescents with disabilities and assist them to meet Havighurst’s (1972) developmental life tasks and therefore experiencing life satisfaction (Havighurst,1972).

CHAPTER 3

3. RESEARCH METHODOLOGY

3.1 INTRODUCTION TO METHODOLOGY

This chapter will discuss the methodology followed to explore the factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with CP in Gauteng. The focus will be placed on the research design utilised for the study, data gathering tools, and the measures utilised to ensure the validity and reliability of data. Lastly, data analysis and ethical considerations will be described.

3.2 STUDY DESIGN

A qualitative approach allows for the collection of evidence to support and answer a question being asked (Mack, 2005). Each participant and their realities are constructed through their experiences and interactions with others, where interviews focused on the different perspectives of individuals and thus themes emerged and developed throughout the research process are emergent and developed (Creswell & Creswell, 2017). The qualitative approach included the voices of the participants, focusing on their experiences and their interpretation of the problem. This current study aimed to understand the facilitators and barriers experienced by late adolescents with CP, where patterns and themes emerged (Creswell & Creswell, 2017).

A qualitative approach allowed for an in-depth understanding of the participants' life experiences and beliefs which they were able to report in detail using semi-structured interviews. Utilisation of the qualitative approach assisted in identifying intangible factors, such as religion and socioeconomic status, which became increasingly relevant during the analysis and interpretation of the data (Creswell, Hanson, Plano, & Morales, 2007; Hammell, Carpenter, & Dyck, 2000; Mack, 2005). This approach further assisted with uncovering the meaning behind the facilitators and barriers which impact the occupational choices of high functioning late adolescents with CP, reflecting on their past life experiences, feelings, and beliefs.

South Africa has been described by local tourist sites as one of the most complex and diverse populations in the world, therefore adopting a qualitative approach that focused on the unique individual perspectives and experiences was implemented for this study, utilizing the qualitative approach additionally generates baseline data against the

paucity of available literature, within SA, especially within Gauteng (Mack, 2005; Jackman, 2019).

A descriptive design was further employed to assist the researcher with describing behaviour, frequencies, and participation based on facilitators and limitations on occupational choices and occupational participation of adolescents with CP. The data received from the research participants were not analysed according to a pre-existing set of rules generated from past studies, but rather specific to the data-derived codes, which were generated from actual data from the study (Lambert & Lambert, 2012).

3.3 STUDY PARTICIPANTS

For the purpose of this study, UNICEF's age bands of late adolescence (15-19 years) were utilised (United Nations International Children's Emergency Fund, 2011). The target population was high functioning late adolescents with CP (MACS levels 1, 2, and 3, GMFCS 1 and 2 between the ages of 15-19 years of age that reside in Gauteng.

However, participants identified by occupational therapists employed by the schools, who readily gave permission included GMFCS 1, 2, and 4, and MACS levels 1,2, and 3. High functioning learners with CP were focused on as the researcher required participants to reflect at an abstract level, which provided rich data during data collection.

3.3.1 Study Sample

Through convenience sampling, initially six government schools for Special Educative Needs (LSEN), which specifically cater to learners with CP were approached. Four of those schools readily gave verbal and written permission to allow research with their learners and within their school premises to be undertaken. Schools were selected through convenience sampling based on the areas that the researcher had access to, as well as the schools which allowed the research to be conducted within their premises (Creswell & Creswell, 2017) (Appendix 17).

Research participants were selected through purposive sampling, using a preselected criterion, which was relevant to the study's research questions This allowed the researcher to explore the knowledge and experiences of high functioning late adolescents with CP (Mack, 2005).

The target population of focus was high functioning late adolescents with CP (MACS levels 1, 2, and 3, GMFCS 1 and 2 between the ages of 15-19 years of age that reside in Gauteng.

Sample sizes were not fixed prior to the commencement of data collection and were determined through the use of theoretical data saturation (Mack, 2005). Data saturation was determined by participant 12 where no additional data was obtained by the researcher but rather repetition of information received by other research participants. The information received was consistent with the research question of the study (Saunders et al., 2018).

3.3.2 Selection Criteria

Occupational therapists based at the LSEN schools were approached by the Researcher, sought permission, and briefed adequately with a take-home information document to guide the identification of possible study participations, as well as contact information to reach the researcher should any questions arise. These occupational therapists assisted with the identification of the relevant research participants, as well as the distribution and collection of consent forms.

Assessments that are routinely performed on the admission of a learner with CP to an LSEN school include an intelligence quotient test (IQ). MACS and GMFCS assessment for appropriate placement within the school, as well as to determine the level of support needed for success.

Table 3.1: Descriptive Characteristics Depicting Inclusion and Exclusion Criteria of Research Participants

Inclusion Criteria	Exclusion Criteria
Learners diagnosed with CP	Learners with any other disability that could impact their ability to successfully engage, participate and perform in chosen occupations
Ability to communicate effectively in English	
Learners between the ages of 15-19.	
MACS level 1 ,2 and 3 (Appendix 1,2)	
GMFCS level 1, and 2 (Appendix 3)	
IQ level 90 and above	
Residing in the Gauteng area	

3.4 DATA GATHERING TOOLS

Demographic information was gathered by the therapists at the chosen schools. These therapists were able to compare the information given by the parent/caregiver on pre-determined consent forms with information from the participants' initial admission to the school. Prior to the start of the interview, demographic information was once again requested from the research participant and was recorded on a pre-determined form to ensure triangulation of data, ensuring validation through review from more than two sources (Appendix 11).

3.4.1 The Occupational Performance History Interview

The Occupational Performance History Interview (OPHI-II), funded jointly by the American Occupational Therapy Association and the American Occupational Therapy Foundation, was designed to gather pertinent information surrounding an individuals' perspective of work, play, and self-care activities, specifically geared towards both the psychiatric and physically disabled populations (Kielhofner & Henry, 1988; Kielhofner, Mallinson, Forsyth, & Lai, 2001).

The researcher gathers information through the use of a client-centered, semi-structured interview covering five thematic areas, namely: activity/occupational choices, critical life events, daily routines, occupational roles, and occupational setting/environment (Kielhofner & Henry, 1988; Kielhofner et al., 2001).

The validity of the OPHI-II has been researched and measured to be valid across different ages, diagnoses, languages, and cultures. This assessment has further been assessed to be valid and readily used without formal training (Kielhofner et al., 2001).

The OPHI-II was therefore chosen as the main data gathering tool as it was suitable for the exploration of the facilitators and barriers regarding the participants' occupational choices and occupational participation. This tool also allowed for probing and clarification of answers received (Barriball & While, 1994) (Appendix 4).

Verbal responses from research participants' were voice recorded, with verbal and written permission from both the participants and parents of participants. The non-verbal responses were supplemented with physical note-taking by the researcher (Creswell & Creswell, 2017).

3.5 RESEARCH PROCEDURE

The research procedure will be discussed in detail in section 3.5 below.

3.5.1 Pilot Study

Once ethical clearance was obtained from the Human Research Ethics Committee at the University of Witwatersrand, an initial pilot study was conducted prior to actual data collection. The OPHI-II pilot study was conducted using two high-functioning late adolescents diagnosed with CP. The pilot study participants presented with similar characteristics to the inclusion criteria needed, however, the pilot study participant responses were not included in the study due to differences in demographic information.

This pilot study was performed to improve the quality and efficiency of the study, as well as to become aware of the main procedures, processes, and sensitivities, such as cultural and religious differences, which need to be respected during data collection. A pilot study was used to prevent the occurrence of a mistake, which could take increased time and money. This also assisted in evaluating the planned interview, which assisted with ensuring that the questions were easily understood with appropriate responses, length of interviews and breaks needed to be given, and to assess whether the wording of the questions needed to be adapted for the South African population (Becker & Bryman, 2004).

The outcome of the pilot study is that the two pilot study participants were able to understand and respond appropriately to the OPHI-II, and no changes were made based on the emergent information from the participants, therefore no changes had to be made to the main data collection tool. Two breaks were needed for one research participant and one break for the other, therefore this needed to be incorporated within the procedure of data collection (Junyong, 2007).

3.5.2 Data Collection

Once approval was obtained from the Gauteng Department of Education (GDE) (Appendix 18), the principals from the required LSEN government schools were contacted and their learners were invited to participate in the study. Written permission from the school principals was requested with the introduction, aims, objectives, and ethical considerations highlighted (Appendix 23). Consent forms were distributed to the principals and subsequently to possible research participants (Appendix 7, Appendix 17).

The researcher requested that the occupational therapists at the chosen LSEN schools identified the adolescents with CP, who adhered to the inclusion criteria. The GMFCS and MACS assessments are routinely performed at the chosen schools prior to admission. These occupational therapists were also requested to identify an area to conduct the interviews, which is both private and comfortable, to ensure privacy and to decrease any possible anxiety experienced by participants. The Interviews occurred in a natural setting where the researcher was sensitive to the people and places in the study, collecting data at the schools of the participants. The interview process occurred in a comfortable, familiar place to the participant, where the researcher was able to gather information face-to-face up and personal, making observations based on behaviour when questions were asked. Utilizing a natural setting assisted in increasing comfort, feelings of safety.

Furthermore, occupational therapists were also requested to distribute the information document, parental and participant consent forms to the possible research participants. Informed consent documents were distributed to participants who were old enough to consent. Once the participant and parental consent forms were returned to the occupational therapists, the date and time were identified which suited both the school and the research participants.

Verbal and written informed assent were obtained from all research participants prior to the commencement of the interview. Research participants were informed of the nature of the research project, a focus being placed on the anticipated risks, benefits, and anticipated risks to make an informed decision. Informed assent was a focus of all research participants, where they were able to verbalize “yes and “no”, The researcher informed and allowed the research participants to ask questions afterward (Creswell & Creswell, 2017).

The researcher utilized a field log which ensured optimal time management. This provided structure of how the researcher spent time on-site during data collection. This field log was compared against transcriptions during the data analysis stage, to assist with recording how the researcher's time was spent (Creswell & Creswell, 2017). In a predetermined layout in a field diary, the researcher was able to note down initial thoughts, experiences, and perceptions throughout the research process. This descriptive and reflective information was utilised to conceptualise and adapt codes and themes throughout the process (Creswell & Creswell, 2017).

Data collection through 60-minute semi-structured interviews (OPHI-II) was conducted, whist adhering to the guidelines set by the Government Department of Education (GDE). This ensured minimal disruption to the research site, research participants as well as to ensure optimal attention and combat fatigue (Creswell et al., 2007).

Data analysis was conducted, focusing on patterns, categories and themes through a bottom-up approach. the data was organized inductively into more abstract collections of information. The researcher then worked back and forth between the datasets which were transcripted and translated onto MAXQDA. The main electronic transcriptions and data collection documents were kept on a password-protected device.

A predetermined interview protocol was utilised to ensure that a consistent, standard procedure was followed. The researcher recorded information by making handwritten notes throughout the interview and through a voice-recording of the interview. The protocol included the following components and allowed for spaces between the questions to record responses (Creswell & Creswell, 2017).

- A heading: The name of the study.
- Predetermined spaces to write in the date, the venue and school being utilized, the name of the researcher conducting the interview, and the interview number of the participant.
- Predetermined questions and probes to be used, as depicted by the OPHI-II manual (Appendix 4).
- The final thank-you statement, acknowledging the research participants' valuable time spent participating in the study.

The number of interviews was not preconceived but rather continued until data saturation was reached. This occurred after 12 interviews, where no additional data was obtained by the researcher but rather a repetition of information received.

3.6 VALIDITY AND RELIABILITY

Strategies for validity and reliability were followed to ensure the accuracy and credibility of the findings of the study (Shenton, 2004). This assisted in ensuring that the researcher's approach was consistent throughout data gathering and the research process. Validity has been considered to be a strength of a qualitative research approach and is based on whether the findings of the study are accurate from the point of the researcher, the participant and/or the reader (Creswell & Creswell, 2017).

Multiple approaches were utilised to ensure the accuracy of the research will be described in the section to follow.

Trustworthiness was maintained through the use of Guba's model (1985); credibility, transferability, conformability, and dependability and occurred throughout the entire research process (Shenton, 2004).

Credibility was maintained through the use of triangulation as using two data gathering tools (audio-recorded semi-structured interviews and observations of non-verbal responses were noted on a predetermined layout of an observational protocol (Appendix 5). This was utilised to deepen the understanding, provided clarity and precision of the data collected, and assisted with the justification for themes that emerged during data analysis (Creswell & Creswell, 2017; Ritchie, Lewis, Nicholls, & Ormston, 2013). Each participant was to be given the option to refuse to participate in the study to ensure that data is collected freely and honestly (Shenton, 2004).

Transferability was maintained as the researcher highlighted the boundaries of the study in terms of restrictions in participants that contributed to the data set. The number of participants that were interviewed before data saturation was reached, the data collection methods, and detailed descriptions of the setting and contexts (Shenton, 2004). This information will assist the reader, or potential future researcher to judge the applicability of the information yielded from the study, and the applicability to similar or other known settings (Thomas, 2010). Conformability and dependability were maintained through the usage of an audit trail. This allowed for a detailed description of the methodology used within the study, including the research design, data collection, and the steps taken to manage, analyse and report the data (Malterud, 2001). A collection of records which is included in the audit trail, includes raw data and written field notes, data analysis reduction and summaries, data reconstruction and synthesis such as the structure of categories, written findings, and conclusions (Halpern, 1984). This will enable the readers to trace the process that was utilised to produce the findings and results of the study (Shenton, 2004).

The research was checked to determine the reliability, consistency, and stability of the research approach utilised. Gibbs (2007) suggested the following procedures be followed to ensure reliability (Creswell & Creswell, 2017).

- Transcripts were checked to decrease errors and identify mistakes that were made during transcription.
- Data and codes were constantly compared throughout the data collection and analysis process. This was performed to decrease the possibility of a drift or change in meanings in the codes which emerged during analysis.
- Member crosschecking was utilised as a strategy to ensure reliability, credibility authenticity and thus increasing the validity of the study (Birt, Scott, Cavers, Campbell, & Walter, 2016). A fellow qualitative researcher was requested to repeat the initial data analysis process, checking the transcription of an interview that yielded the most pertinent information, comparing initial emergent themes and categories. This ensured consistency of the findings over time, across the interview process, and through different observers, This ensured that the researcher gained feedback on the data regarding the findings, interpretations, and conclusions. This also was used to ensure triangulation of codes and themes which emerged during data analysis (Birt, Scott, Cavers, Campbell, & Walter, 2016). The fellow researcher who assisted with checking the initial codes and themes was satisfied with the accuracy of the codes and themes which originally emerged, however, added additional descriptive words to the initial codes and themes (Creswell & Creswell, 2017).

3.7 ANALYSIS OF DATA

The interviews were conducted by the researcher and transcribed immediately by a professional within the ambit of research. Qualitative research has been described as ongoing and fluid, therefore processing the emergent information as the interviews are conducted as it assists the researcher with ideas and topics. The open-ended questions changed slightly as well as became more refined during the increasing understanding of the problem. This assisted with processing the information and findings immediately. Data analysis was performed hand in hand with data collection and the development of the write-up of findings, as the following questions to open-ended interview questions were adapted and evolved as data analysis emerged. This was performed to ensure the correct information was being gathered, to determine the quality and quantity of information emerging from research participants (Creswell & Creswell, 2017).

The use of MAXQDA, a computer data analysis programme was utilised, incorporating thematic analysis for interpretation (MAXQDA, 2017). The use of MAXQDA assisted in helping the researcher organise, sort, locate and compare the information collected

during data analysis (Creswell & Creswell, 2017; MAXQDA, 2017). MAXQDA further supported the researcher to locate and determine whether responses that have been previously coded, are responding to the code similarly or differently (Creswell & Creswell, 2017). Thematic analysis was applied to assist the researcher to interact appropriately with the data received (Creswell & Creswell, 2017).

Thematic analysis, described by Creswell and Creswell (2017) the researcher identified themes interactively which are 'told' by the research participants. This was utilised to analyse and interpret the findings obtained from the participants during semi-structured interviews. The data analysis in the Qualitative Research process according to Creswell and Creswell (2017) was followed to assist the researcher with the analysis and interpretation of data is highlighted in Figure 3.1 below, following a brief description of the steps followed (Creswell & Creswell, 2017).

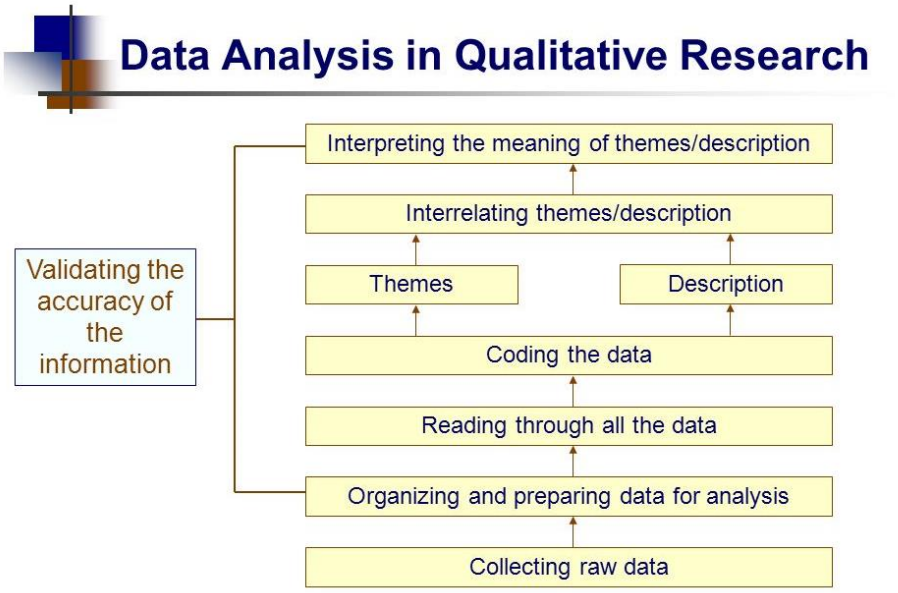


Figure 3.1: Data Analysis in Qualitative Research

adapted by Creswell & Creswell (2017)

Permission of usage of figure granted by SAGE publication (Appendix 26)

Step 1: The researcher organised and prepared the raw data for transcription of the interviews by an external party, analysis for transcription of the interviews and typing the field notes that were observed in the interviews (Creswell & Creswell, 2017).

Step 2: The researcher read and re-read the data that was collated in step one. This allowed the researcher to gain a sense of overall meaning and reflect on the information

that was collected. The researcher was able to critique the information received and record the general ideas that were beginning to emerge. Notes surrounding the general thoughts about the data were typed in the margins of the transcribed interviews via MAXQDA (Creswell & Creswell, 2017).

Step 3: Coding of the emerging data was initiated during this step. This involved organising the data into chunks and then into a word/phrase taken directly from participants' responses during interviews, also referred to as 'in Vivo' terms (Creswell & Creswell, 2017). Coding was developed by using a combination of emerging information received during data collection and from predetermined codes from literature.

Step 4: The coding process was utilised to generate a description, detailed information surrounding the participants, setting as well as the themes and categories, which emerged (Creswell & Creswell, 2017). The coding was utilised to generate themes and categories for the study. This also assisted to maintain and display the multiple perspectives of participants, which were attained during data collection highlighting the associated different and diverse quotations (Creswell & Creswell, 2017).

Step 5: The description and themes were further explored and represented in a table and in a narrative passage to convey the findings of the data analysis (Creswell & Creswell, 2017). This included a detailed discussion of themes, categories, subcategories, and codes, which emerged; the interrelatedness of themes was also highlighted (Creswell & Creswell, 2017). Descriptive information surrounding each participant was represented primarily in a table, and later pertinent information surrounding the participants' assessments and diagnoses was represented in a graph.

Step 6: Themes that emerged were further explored, interrelated and an interpretation was then linked to the findings of the study. The interpretation was derived from the comparison of findings from the literature. This step assisted the researcher to be able to confirm past literature or suggest new questions, which needed to be asked, especially within the South African context. The data was then interpreted through the use of a 'theoretical lens', which assisted in the call for action which became evident, to assist with change (Creswell & Creswell, 2017). This will be discussed further in Chapter 5.

3.8 ETHICAL CONSIDERATIONS

Prior to data collection, ethical clearance was obtained from the Medical Human Research Ethics Committee from the University of Witwatersrand, Gauteng. Ethical clearance number: M:180969. (Appendix 6).

Permission to include learners and utilisation of LSEN governmental schools were applied for and granted by the Gauteng Department of Education (GDE). (Appendix 18).

It is important to note the special considerations that were followed as stipulated by the GDE in terms of dates as limitations exist regarding the conduction of research during the beginning of the year as well as the last quarter.

LSEN governmental schools were then contacted, requesting permission to gain access to the site and to research participants within their schools (Appendix 23). Four (4) of the six (6) schools approached readily gave verbal and written permission to grant access regarding the usage of their students and premises to conduct the research. Written permission was sought from research participants and their parents (Appendix 7, 20, and 21).

The study's aim and research procedure were explained to the research participants prior to the commencement of data collection. Participants were given an opportunity given to ask questions afterward. It was of utmost importance that the research participants understood the purpose of the research and what is expected of them if they chose to participate (including the length of the interview, the expected risks, and benefits associated with participation, and how their privacy will be respected). The information, question, and answer session were conducted to ensure that the research participant is making an informed decision as well as to avoid deceiving the research participants (Creswell et al., 2007).

Participants' voluntary participation was emphasised to them throughout the process, with the option of withdrawing from the study at any given time with no negative repercussions for their decision. The information was given to them in a language and at an educational level that the participants could understand, with limited jargon to ensure that the research participants made an informed decision regarding their participation. This ensured respect for the research participant as well as to ensure that

the participant was comfortable and at ease (Mack, 2005). Informed consent and written permission were requested on a predetermined document. (Appendix 5).

The researcher verbally explained that there was no reward for their participation in the study, however, the researcher will share the final report with the GDE, the schools which participated as well as the research participants to avoid exploitation of participants and to provide appreciation and respect for their contribution to the study (Creswell & Creswell, 2017).

To protect the rights, values, needs, and desires of research participants, parents, and other stakeholders who are involved in the study, the following ethical considerations were applied (Creswell & Creswell, 2017).

3.8.1 Minimising Risk of Harm: Non-Maleficence

Harm to the researcher, research participants, and stakeholders were minimized. This was predetermined prior to data collection, treating participants courteously and with dignity, which was achieved by careful decision making regarding the process and questions which were asked, as well as having adequate training, which was offered by the University of the Witwatersrand. The research aims to do good, by adding to the body of knowledge surrounding the factors which influence the occupational choices of high functioning adolescents living with CP (Roberts & Priest, 2010).

A full debriefing was performed by the researcher and the possibilities of distress were communicated to the participants prior to data collection, with the knowledge that the interview would be stopped and referred to the school psychologist should they become distressed due to recalling of past experiences (Roberts & Priest, 2010).

Arrangements were made with school councillors prior to data collection, to be on hand during the interview process, should the councillors be needed to assist if distress did occur. A printout of local councillors was kept at hand in the case of the participant wanting to seek an independent party to assist and manage their past experiences (Roberts & Priest, 2010).

3.8.2 Beneficence

Beneficence has been described by Roberts et al., (2010) as research being conducted should aim to do good, whether it is directly to the research participants or others who will benefit in the future (Roberts & Priest, 2010).

Research participants were informed, verbally and in writing, that participation in the study may not have any immediate benefit to the participant, participation will only require the participants' time (Roberts & Priest, 2010).

Information gathered from the research aims to add to the body of knowledge surrounding the factors, which influence the occupational choices of high functioning late adolescents diagnosed with CP within Gauteng. All participants were enthusiastic surrounding their participation in the research, in the hope that other adolescents with CP who experience similar negative experiences surrounding their disability, will emerge and will be addressed so that others will have a better experience and improved quality of care (Roberts & Priest, 2010).

3.8.3 **Obtaining Informed Consent**

The research participants and their parents/legal caretakers were informed about the aims, benefits, risks, and the requirements of the participant in a language and terms which they could understand. This was ensured by a written participant and caregiver information sheets; thus, informed consent could be given by both parties (Roberts and Priest, 2010).

These documents were sent home by occupational therapists at the chosen schools, which readily permitted participation in the study. These documents were sent home prior to data collection, to ensure that the potential participant has adequate time to read, digest, and seek independent advice from an external party. This will assist with ensuring that participants and parents make an informed decision regarding participation in the study (Roberts & Priest, 2010).

Prior to the actual conduction of data collection, the aims, benefits, risks, and requirements were once again highlighted in a language that is understandable to the participant. An opportunity was given to ask questions followed by a request for signed assent from the participants. This was conducted to ensure informed consent (Roberts & Priest, 2010). (Appendix 9).

Seeking consent from research participants was not conducted as a ‘once off’ activity before data collection, but rather continually requested throughout the research process. The researcher constantly recalled their initial consent and requested if they would continue with the interview or alternately, given the right to withdraw from the study without penalty (Roberts & Priest, 2010).

3.8.4 **Protecting Anonymity and Confidentiality**

De-identification and privacy were a priority and maintained to the best of the researcher's ability, due to the personal and sensitive information, which emerged during the process. The research participants were informed concerning the procedures, which were utilised to ensure their anonymity and confidentiality. All the participants' personal information such as name, date of birth, and results of the assessment will be kept confidential and only known to the researcher and supervisor. To ensure confidentiality data will be coded with no names attached and this data will be kept in a secure location by the researcher (Roberts & Priest, 2010).

Anonymity and confidentiality were ensured through the usage of a private area whilst conducting the interviews. Names and personal information during transcription were omitted and replaced with appropriate pseudonyms. This will assist in ensuring that the research participants remain as anonymous as possible, throughout the entire research process.

Information was stored on a password-protected device, which the researcher, supervisor, and the professional external transcriber had access to. Electronic data, such as the voice recording will be backed up on a password-protected device regularly and will be disposed of appropriately, to ensure that the data was able to be accurately reported, interpreted, and verified (Roberts & Priest, 2010). The research records will be kept for at least 5 years and possibly longer, the data will be retained until there is no reasonable possibility that the researcher will be required to defend against an allegation of scientific misconduct. The guidelines set out by the Data Protection Act (1998) were followed to ensure ethical research whilst protecting research participants, where guidelines for storage of data and disposal of information were adhered to (Roberts & Priest, 2010).

3.8.5 **Avoiding Deceptive Practices and Competence**

This research study was not deceptive in any way, all information was disclosed to the parents, research participants, and relevant stakeholders through the utilisation of a question-and-answer session before data collection. All relevant parties received an attached written information document to ensure informed consent. Provisions for participants to opt-out of the research were constantly offered throughout the research process, with the opportunity to refuse the use of their answers in the study (Roberts & Priest, 2010).

Competence was maintained by informing the parents and research participants regarding both the researcher and supervisors' skill set. The research participant was also informed about the approved ethically sound research proposal and the University of Witwatersrand approved research training that the researcher underwent to provide an ethically sound and accurate research study (Roberts & Priest, 2010).

Contact details of the researcher, supervisor, and chairperson of the Human Research Ethics Committee (Medical) were given to potential research participants, parents, and relevant stakeholders to contact if they had concerns, questions, or queries (Roberts & Priest, 2010).

There were no Potential conflicts of interest, and this was disclosed to the research participants and parents. Research participants were also made aware of the funding and sponsors for the study, University of Witwatersrand, Heath Science Faculty Grant (Creswell & Creswell, 2017; Roberts & Priest, 2010).

3.8.6 Providing the Right to Withdraw from the Study

In accordance with the World Medical Association Declaration of Helsinki (WMADoH), the research participant was informed of their right to withdraw from the study at any given stage, without reprisal to respect the research participant's autonomy and right to express their personal choice (World Medical Association, 2013; Roberts & Priest, 2010). Research participants were also informed that they can request that information which they volunteered during data collection, should not be used within the study. This information was conveyed to research participants in writing and verbally, before and during the commencement of the interview (Roberts & Priest, 2010). No participants withdrew from the current study.

3.9 DISSEMINATION OF FINDINGS

Wilson, Petticrew, Calnan, and Nazareth (2010) describe the dissemination of findings as a planned process that assists the researcher in enhancing the findings of the study (Wilson, Petticrew, Calnan, & Nazareth, 2010). The findings of the study will be presented to the research participants and their parents, GDE, their stakeholders and school governing bodies, and the South African Cerebral Palsy Association (SACPA).

The researcher ensured a hard and electronic copy of the completed study is made available to the GDE Research Coordination Unit, directors of schools associated with

the research, the University of Witwatersrand, and the Occupational Therapy Association of South Africa (OTASA).

3.10 CONCLUSION TO METHODOLOGY

The researcher utilised a qualitative approach, with a descriptive design that focused on personal experiences and perspectives. Semi-structured interviews were conducted with 12 research participants which yielded rich data, and consequently data saturation.

Permission and ethical clearance were granted from the Medical Human Research Ethics Committee from the University of Witwatersrand, Gauteng, Gauteng Department of Education (GDE), principals, and occupational therapists from chosen LSEN governmental schools as well as the research participants and parents.

Use of the OPHI-II was utilised. Strategies for validity and reliability were followed to ensure accuracy and credibility of the findings of the study, such as checking transcripts, peer review, comparing data and codes throughout data collection and analysis. Trustworthiness will be maintained through the use of Guba's model (1985); credibility, transferability, conformability, and dependability and occurred throughout the entire research process.

Data analysis was conducted through thematic analysis, with the aid of MAXQDA. Each step of data analysis in Qualitative research by Creswell and Creswell (2017) was described in depth.

This chapter explored, highlighted, and described the research methodology utilised to explore the factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with CP in Gauteng. The methodology chapter also included the target population, sample, data collection as well as the strategies which were utilised to ensure ethical standards are upheld and to ensure reliability and validity of the study.

CHAPTER 4

4. FINDINGS

4.1 INTRODUCTION TO FINDINGS

In chapter four, the findings of the study will be presented. The chapter will be outlined as follows: a description of the study participants, the main themes which arose from the OPHI – II semi-structured interviews, describing the facilitators that impact the occupational choices of high functioning late adolescents with CP, followed by their barriers that impact on the occupational choices of high functioning late adolescents with CP. The data from 12 research participants were analysed through the use of thematic analysis. Themes that emerged were direct quotes that were taken from the transcriptions of the interviews.

Table 4.1: Classification of CP among Research Participants (n=12)

Participant	Age	Gender	Location	CP Classification	GMFCS	MACS	Medication
1	17y 3m	Male	Soweto	Spastic quadriplegic	IV	2	Nil
2	16y 2m	Female	Central Joburg	Spastic diplegia	IV	1	Nil
3	15y 7m	Female	Soweto	Spastic diplegia	IV	2	Nil
4	15y 8m	Male	Vosloorus	Spastic quadriplegia	IV	3	Nil
5	17y 10m	Male	Soweto	Spastic hemiplegic	I	2	Nil
6	18y 1m	Female	Bedfordview	Spastic hemiplegia	I	2	Nil
7	15y 4m	Female	Magaliesburg	Spastic hemiplegic	I	1	Nil
8	17y 2m	Male	Roodepoort	Spastic hemiplegic	I	1	Nil
9	15y 5m	Male	Krugersdorp	Spastic hemiplegic	I	1	Nil
10	16y 5m	Male	Sterkfontein	Spastic hemiplegic	I	2	Nil
11	15y 1m	Male	Randfontein	Spastic quadriplegic	III	2	Nil
12	17y 7m	Male	Krugersdorp	Spastic hemiplegic	III	2	Nil

4.2 DESCRIPTION OF THEMES ARISING FROM SEMI-STRUCTURED INTERVIEWS

4.2.1 Demographics of Study Participants

Data saturation was obtained after 12 research participants. Table 4.1 above depicts the pertinent clinical characteristics and demographic information of the research participants, which were included in the study. The chronological age ranged from 15 to 19 years; the mean age being 16 years 5 months. There were 67% male participants and 33% females who participated in the study. The location of the participants was scattered along Johannesburg, Gauteng, with Soweto and Krugersdorp both yielding two participants from each suburb.

The classification of CP was broken into majority spastic hemiplegia (58%), followed by spastic quadriplegia (25%), and lastly spastic diplegia (17%). The majority of the participants were assessed to be functioning GMFCS level 1 (50%), followed by level 3 (17%) and lastly level IV (33%). No participants were currently taking medication at the time of data collection.

The MACS classification of the research participants was broken down into majority MACS level 2, yielding 7 participants, followed by MACS level 1, yielding 4 participants, and finally, a single research participant who was assessed to be at MACS level 3.

However, some of the voices from participants are not heard. It is interesting to note that the voice of P4 portrays the loudest responses as a 15 year 8-month-old male who is represented with 21 quotes, while P5 (17-year-old male) and P (11) (15-year-1 month female) are not heard with zero quotes each. Participant 1, a 17 year 3-month-old male is also loud and clear with 18 quotes, while participant 12, a 17 year 7-month-old is only represented once.

The four female participants, namely Participant 2 (16 year 2-month-old), Participant 3 (15 years, 7-month-old), Participant 6 (18-year, 1-month-old), and Participant 7 (15 years, 2 months old) each have 4, 6, 6, and 5 quotes, respectively.

Table 4.1 above depicts the demographic and clinical characteristics of the research participants from the data collected. This research yielded three themes, namely.

- Inclusion in life's decisions and occupational choices
- Am I good enough? (feelings of inferiority)
- I am not safe

Theme 1 relates to the first objective, relaying the facilitator, which emerged as impacting positively on the occupational choices of high functioning late adolescents with CP. Theme two and three relate to the second objective to explore the barriers which impact the occupational choices of high functioning late adolescents with CP.

4.3 DESCRIPTION OF THEMES ARISING FROM SEMI-STRUCTURED INTERVIEWS

Table 4.2 below summarises the themes, categories, codes, and sub-codes, which emerged from the data analysis surrounding the facilitators that impact the occupational choices of high functioning late adolescents with CP.

4.4 THEME 1: INCLUSION IN LIFE'S DECISIONS AND OCCUPATIONAL CHOICES

The research question for this objective is: what are the facilitators that impact high functioning late adolescents with CP. Inclusion in life's decisions and occupational choices was the main theme that emerged during data collection and analysis as depicted in Table 4.2 below. The categories contributing to this theme are familial resources and finances and attendance to a school for learners with special needs.

Table 4.2: To Explore the Facilitators that Impact on the Occupational Choices of High Functioning Late Adolescents with CP (n=12)

Themes	Categories	Sub-categories	Codes
Inclusion in life's decisions and occupational choices	**Familial resources** and finances	**Family dynamics** **Do things as a family**	**I spend time with family, going out or at home** ▪ We'll go out to lunch or we will stay at home and watch a movie ▪ My brother and I usually play tennis ▪ I go out to the park with my sister ▪ Sometimes we go out with my brother
		Use of technology	**Playing video games and iPad** ▪ I play PlayStation I watch TV then check out different things on the iPad
Inclusion in life's decisions and occupational choices	**Attending a school for learners with special needs**	**Acceptance – I belong**	**I feel normal and accepted, I feel more comfortable around people just like me** ▪ I feel normal around them ▪ I feel more accepted around them ▪ I compete with people who are like me ▪ They don't judge you ▪ Makes you feel like all eyes aren't on you anymore, more comfortable ▪ Being around my peers, they understand what I'm going through **I get support and they accommodate my needs** ▪ People are very accommodating ▪ I get support ▪ The school environment. its human for me, I can do things on my own **Makes life more bearable** ▪ Finding out who you are in a space of people who are tin the same situation, makes life more bearable **Sports are very important and has changed my life** ▪ Athletics has changed my life ▪ Sports are very important ▪ The first time I went to sports, it changed my life **Sense of accomplishments** ▪ I get to represent the school for sports ▪ A typical good day would be winning at sports, I'm number one ▪ They were looking for a star, I got 3 gold and 1 silver ▪ Winning…winning at sports because I am number one for me, I can do things on my own
	Attending a school for learners with special needs	**Acceptance – I belong**	

Participants indicated positive feelings and concepts surrounding their experiences of inclusion within family events and outings through the use of resources to facilitate participation in occupational choices. Acceptance and feelings of belonging have been associated with attendance at a school for learners with special needs. The categories have been found to facilitate and increase the high functioning late adolescent with CP's occupational choices.

Adolescents with disabilities want to be included and not just accommodated for, as they feel that inclusion is a right, and being excluded has made them feel that their rights are being violated.

4.4.1 Familial Resources and Finances

Four research participants, whose families do not rely on Care Dependency Grants (CDG's) identified that they spend much of their free time with their families going out into the community or together at home. Three research participants identified that they enjoyed spending time with their families either at home or out in the community.

Familial resources have been noted to increase the occupational choices available to the adolescent with CP, as four research participants highlighted high-end technology which research participants who depend on CDG may not have access to. This is seen in the quote by P (8) below.

P (8): "We go to the Hartbeespoort dam every weekend…We've got a place there in Harties, so we play golf and go on our boat. And sometimes we play tennis and stuff, so we're quite busy over the weekend, in fact, last week we were in Brazil."

4.4.1.1 Family dynamics: do things as a family

Four research participants felt that support and positivity from their immediate family, as well as familial finances, were important facilitators to their occupational performance. Spending time with their family, either at home or in the community, assisted the adolescent with CP to feel included within the family and community, increasing the occupational choices for the adolescent with CP. This is seen in the quote by P (6) below, where she showed normality, ownership, and feelings of acceptance in her tone of voice.

P (6): "We will all go out to lunch or we will stay at home and watch a movie".

I spend time with family, going out or at home.

This secure and safe participation, inclusion, and belonging within the family translates into easier inclusion within the community, as the adolescent with a disability additionally feels safe and comfortable to participate in activities that they want or need to perform, increasing their occupational choices and connectedness to others. The need to belong and contribute to the community has been noted to be important discrimination for their QoL. This is seen verbatim P (6) above as well as P (7) below.

P (7): "I go out to the park with my sister…"

Parents who can financially afford to spend time with their child with CP, conveyed positive views towards acceptance and inclusion within the family and community, positively influencing their occupational choices. The family involvement and inclusion in the lives of high functioning late adolescents with CP is evident in the quotes below by P (8) and P (4):

P (8): "…my brother and I usually play tennis in the week".

P (4): "My mom, sister and I …sometimes play board games together".

4.4.1.2 **Use of technology**

The use of technology, such as phones, gaming devices, and tablets emerged as a facilitator to social participation and occupational choices available to the adolescent with CP as mentioned by participants who do not receive a CDG. Participant (8) highlighted an assistive device that he did not necessarily need for participation but stated that it made his life a little easier. This is seen in the quote below.

P (8): "I have this device which helps me kick my leg out abit further. I don't need it, but my parents imported it from another country."

The use of technology is used to keep in contact with peers as well as constructive use of leisure time, posing as a facilitator to the adolescent with CP's occupational choices.

"I like to play on my phone"

Six research participants expressed that they prefer to communicate with their peers through technology such as with a cell phone. Applications such as WhatsApp have been identified by the research participants as being a pertinent facilitator to their social participation, as seen verbatim in the quote by P (10) below. The utilisation of technology such as a cell phone has been perceived as a facilitator to the occupational choices of adolescents with CP.

P (10): "In my free time, I'm on my phone. I use WhatsApp".

Three research participants identified that they utilise their phones to watch videos on an application, YouTube. Watching videos on the internet and through the application assists the adolescent to make constructive use of their time, as long as they have access to the internet, airtime, and data.

Utilisation of their phones and being able to afford internet and data costs assists the adolescent to be included in pertinent video topics, access to information as well as having the choice to surf the internet and the various topics available. This is seen in the quote below by P (6).

P (6): "I watch videos on the internet …"

Playing video games and with the iPad.

Three research participants expressed that playing games on the PlayStation and utilising the iPad to search the internet and watch videos have been facilitators to their participation and constructive use of leisure time. The use of technology has been identified as a facilitator to the occupational choices of adolescents with CP. This is seen by P (3) and P (8) below.

P (3) "…I play with my PlayStation."

P (8) "… I watch TV then check out different things on the iPad."

4.4.2 Attending a School for Learners with Special Needs

All of the research participants expressed that attending a school for learners with special needs, where their physical environment is adapted for them, and there is the availability of supportive teachers as well as being able to socialise with their peers who have different forms of impairments, make the participants feel 'normal and accepted'. This is seen verbatim by P (9) below.

P (9): "I feel more accepted around them… I feel normal around them."

Attending a school for learners with special needs also assists with opportunities and provisions for the performance of sports, which they would have previously been excluded from. The importance of sports to participants is seen in the quote by P (9) below.

"P (9): "A typical good day would be winning at sports, I'm number one".

The attendance of a school for learners with special needs also allows the adolescent with CP to compete with peers who are leveled along with the same occupational ability, leaving the adolescent with a sense of accomplishment, and a feeling of

inclusion, positively impacting their occupational choices. This is seen in the quote by P (9) below where feelings of inclusion are evident.

P (9): "Because like, I compete with the people, who are like pretty much the same as me. And I feel like normal around them. Sometimes when I'm around like normal people, I will like to feel weird or weak or something like that..."

"I feel normal and accepted, I feel more comfortable around people just like me"

All research participants indicated that they felt acceptance and inclusion by attending a school for learners with special needs which cater for disabilities and impairments. Participants felt that attending school with individuals with similar needs assisted the adolescent with CP to fit in and feel "normal", more understood and therefore elevating their sense of competence and confidence to attempt new activities and participate in opportunities which they would have previously shied away from, such as sports and competing with them who are like them. They also do not judge them. This is seen in the quote by P (1) below.

P (1): "Because they…they don't judge you in my class, - Look at you. No, they welcome you with good hands, and they know that this is a place for you. And you feel happy here."

Having a sense of belonging and acceptance is found to be a facilitator to the occupational choices for adolescents with CP.

All research participants revealed that attending a school for learners with special needs enhanced their feelings of inclusion, which assisted the participants to feel "normal" in a world where their disability is often the first aspect that is noticed. This is seen in the quote by P (4) below.

P (4): "'Cause, like seeing…seeing different kids, or you know, you know with like the system we be sometimes, we be going out somewhere and, all eyes are on you basically in an instant. Yea, that makes me feel so uncomfortable. It is just like when I'm around people like me, I get to feel normal again. Yeah."

Participants further felt that they were more readily understood and accepted as they are learning amongst their peers, who have their own set of impairments, which is seen in P (4) in the quote below. This assisted the participants to fit in and feel more comfortable and competent to attempt new opportunities and activities therefore increasing the occupational choices available for participation.

P (4): "Being around all my friends and peers, 'cause they understand what I'm going through, cause they are going through the same thing."

I get support and they accommodate my needs

Five research participants voiced that they received additional emotional, physical, and educational support, especially surrounding their limitations. They further explained that they receive support from their peers and teachers at a school for learners with special needs. This is seen by the quote by P (4) below, where he feels that staff and peers at his school give him the support that he needs.

P (4) "…people are very accommodating…basically, I get support."

Gaining additional emotional and physical support, coupled with decreased environmental physical limitations, such as the school structure including ramps; has been noted to facilitate occupational choices and foster inclusion within the school environment. P (4) below describes the experience of school as being somewhat normal for him, where he is not constantly reminded of his limitations.

P (4): "School environment… It's kind of human for me, 'cause I can go anywhere at any time without having a feel of there is no accessibility or there's no way for me to get up there without any help."

P (4) explained that attending a school for learners with special needs, makes life easier and bearable for him. Attending a school for learners with special needs assisted the participant in feeling competent, confident, accepted, and included which facilitated the occupational choices available to him.

P (4): "…: Learning, and basically finding who you are in a space of people that are just like, people around me who are in the same situation like I am. And it makes life more bearable."

"Sports are very important and has changed my life"

Six research participants stated that though attending a school for learners with special needs, they were presented with opportunities to play sports that were adapted for their disabilities.

The opportunity and inclusion associated with playing sports and being part of a team increased their self-confidence and competence in their abilities, which participants considered to be very important to their self-identities. Being offered the opportunity to play adapted sports is considered to be a facilitator to the occupational choices of

adolescents with CP especially from a notion of the neuro-physiological value of the experience of pleasure as part of occupational balance. The importance of having the opportunity to play sports is seen in the quote by P (9) below.

P (9): "The first time I went to sports, it changed my life…"

Three research participants felt that having the opportunity to play adapted sports is important and has changed their lives. This is seen verbatim by P (9) and P (1) below. Participants reflected that school for learners with special needs, where the primary focus is on more than just academics, is a facilitator to the occupational choices offered to the adolescent with CP and is associated with positive participation within these choices.

P (9): "I would say that athletics has changed my life."

P (1): "sports are very important to me".

'Sense of accomplishment'

Four participants expressed that participation in adapted sports, which are offered by schools for learners with special needs, gave them a sense of accomplishment. Their participation and competitiveness, which are linked to their self-esteem and confidence in their abilities are evident in the positive tone in which they spoke. This is seen by P (1) in the quotes below. Participation, competence, and accomplishment in activities such as sports are a facilitator to the occupational choices of adolescents with CP.

P (1): "I get to represent the school for sports."

P (1): "…they were looking for a star, I got the gold and 1 silver."

*P (1): "winning…*winning at sports because I am number 1!"

CONCLUSION TO THEME 1: INCLUSION IN LIFE'S DECISIONS AND OCCUPATIONAL CHOICES

The attendance of a school for learners with special needs usually includes adapted sports as a possible occupational choice. Participants indicated that being able to play and excel at sports is a big facilitator to their occupational choices, often having a positive effect on the participants' self-esteem and confidence. Table 4.3 below summarises the themes, categories, codes, and sub-codes that emerged from the data analysis surrounding the barriers that impact the occupational choices of high functioning late adolescents with CP.

Table 4.3: To Explore the Barriers that Impact on the Occupational Choices of High Functioning Late Adolescents with CP

Theme 1	Categories	Sub-Categories	Codes
Am I good enough? *(Feelings of inferiority)*	**Family excludes them** *Do not do things together as a family*	**Decreased family support** *Not involved in family occupations*	**My family does not see me as needing the same things as a "normal person"** I just want to be with my mother, but she doesn't see that My dad doesn't care about my stuff, only my sisters Family does not want to do things with me But it's also hard for me, cause it's like she doesn't know what I go through every day. It becomes very emotional…. She doesn't have to go through all the things I go through, cause she's normal. I prefer to be on my own.
			Family sees me as "useless" My mother asks" who is going to help you when you need the toilet?' My child is "useless" My dad feels that his son is useless
		Family stigma, blame and guilt surrounding disability	**Everything is my fault** My mother said it's my fault that my hand is like this My mom blames me for my disability
	Community Stigma	**Bullying by peers**	**The bullying doesn't stop** They make jokes, jokes around me Kids tend to be mean They always bully you, they always laugh at you It's kind of hard for you to fight back, the only thing you have the only thing you can fight back with is verbally My childhood was pretty rough The bullying doesn't stop They always bully you
Am I good enough? (Feelings of inferiority)		**Bullying by peers**	**Isolated by group of friends (causing social isolation)** During the initial years where I had a big group of friends, and they gradually isolated me out of the group, so that led to me becoming more a-social [they] just leave me out. And that just felt, I felt cast out, because I felt like I was just there and no one is getting along with me, and no one is talking to me. And I'm just quiet, and I don't feel, I just feel uncomfortable.

Theme 1	Categories	Sub-Categories	Codes
Am I good enough? *(Feelings of inferiority)*		**Judgment by community members**	**I am judged by what I look like rather than who I am** I am judged by what I look like rather than who I am They know you by looking, but they don't know the inside of you They think I'm stupid and dumb, because of my wheelchair
			They do not understand me, they are normal They don't understand me At a normal school [they] don't understand me People are not understanding But it's also hard for me, cause it's like she doesn't know what I go through every day. It becomes very emotional. She doesn't have to go through all the things I go through, **cause she's normal**
		Judgment by community members	**Community members stare and make negative comments** They talk about you; they talk about your disability on the streets People always have things to say, they are never out of topics Sometimes I feel like I don't want to be watched They think I'm a ghost or something
	Right now, I'm not getting any air: *Social Isolation*	**Decreased socialisation**	**Decreased social skills/ socialisation can be challenging.** Social aspect of school stresses me out The social aspect of school… can be challenging You have more problems socially, than any other normal child would It's very hard to communicate and socialise Socially I am facing a lot of difficulties
			Avoidance of social situations I keep my privacy by not interacting with others I think I'm okay being alone I just sit and watch others so basically, I exclude myself I don't really interact with people that much I don't really talk to people

Theme 1	Categories	Sub-Categories	Codes
			I can't do this, I can't do that, so basically, I exclude myself
			I'd rather sit at home than be bullied by others
			I'm alone and do not have any friends
			I don't have any friends
			Most of the time, I'm by myself
			I don't go out that much, I basically have no friends
			I just sit and watch others
			I don't really talk to people
			I can't do this, I can't do that, so basically, I exclude myself
			right now, I'm not really getting any air, I just stay at home
			I'm alone
		Lack of familial finances	**No money for social media and socialisation.**
			Can't go to the mall, no money
			There's always no money
			No money for WIFI or data to go on social media
	Dependence on others	**My disability limits me**	**I'm tired of asking for help (so I don't)**
			People have to help me
			I'm tired of asking people to keep helping me
			My disability depicts what I can do and stops me from doing what I want.
			My disability stops me from doing what I want
			Can't walk for long periods of time
			My disability has affected me my whole life
			My body controls me, I can't control my body
			I can't use my wheelchair in the house, I usually just sit on the couch
			I can't do this; I can't do that…
			Parents ask, who is going to help you when you need the toilet, its true!
			You must ask for help with every single thing. You lose your dignity
			Not enough energy and time to do everything I need

4.5 THEME 2: AM I GOOD ENOUGH? *(Feelings of Inferiority)*

The research question for this objective is: what are the barriers that impact the occupational choices of high functioning late adolescents with CP. The categories contributing to this theme are not involved in family occupations, community stigma, social isolation, and dependence on others.

Participants indicated feelings and concepts surrounding their experiences of decreased family support with associated family stigma, judgement by community members, bullying by peers, and isolation. These are all contributing factors, which excluded high functioning late adolescents with CP, leading to feelings of inferiority, and as a result, feeling that they are not good enough.

4.5.1 Family Excludes Them (*Do Not Do Things Together as a Family*)

This category yielded two sub-categories: decreased family support and family stigma and guilt surrounding disability.

'My family does not see me as needing the same things as a 'normal' person'

Four research participants described that their daily occupations did not readily involve doing things as a family. Participants indicated that their families are not engaging with them and see them in a "disabled role" which may create some confusion due to not knowing what to do with them and how to include them in their lives. They can be seen as a helpless individual, a half-person, where family members need to do things for them, and they do not hold a valid opinion, leading to exclusion and therefore limited occupational engagement and choices. This is seen verbatim below by P (3) who relayed his constant exclusion from pertinent members of his immediate family.

P (3): "…the only problem at home, it's, no one, no one else to do what I want them to do. For me, like I want them to say to my sisters, let's go for a jog, she doesn't want to, she wants to do her own thing. So, I try and guess, do my own thing."
P (3): "I started to realise that [my father] doesn't want me to live at home. And I decided to do my own things."

Participants further relayed experiencing decreased family support as well as the family stigma surrounding disability and associated guilt that they experienced. Participants felt as if they were seen by their family as "not normal" and expressed feelings of inferiority and a decreased support from their family. This is seen in verbatim below by

P (3) where he revealed exclusion within his immediate family, leading to feelings of worthlessness and loneliness.

P (3): "I just, I can't sit near him, or talk to him, or say anything to him…: It feels like maybe his son is useless or something, I don't know…: I don't feel like talking to my father... But when I talk to him about my stuff, he doesn't care about mine. He cares about my sister. I started to realise he doesn't care about me and I started to, I started to do my things on my own way."

As seen verbatim above, P (3) felt that his parents did not see them in the same light as his 'normal' siblings and that his daily activities were not considered as important as a "normal person" to be given attention. This led to participants feeling unsupported, rejected, and unimportant, therefore wanting to exclude themselves to protect their self-esteem and development in skills, limiting their occupational engagement and choices.

Four research participants experienced isolation from their families, whereas they craved family time and wanted to be accepted and involved in their family's lives. This exclusion is seen verbatim below where P (2) felt as if her mother was purposefully avoiding spending quality time with the participant, leading to feelings of worthlessness and decreased importance in her family's life.

P (2): "Right now, it's just wondering if I'm ever going to get back with my mom …'cause she just seems to have left…, and I just want to be with her. And she doesn't seem to understand that, if she does if she did, she wouldn't it. "

Participant (4) expressed feelings of a lack of emotional support from members of his family. The participant, as stated verbatim below, feels as if his family does not fully understand his disability, his needs and often feels misunderstood by pertinent members of his family. This lack of emotional support leads to the participant feeling unimportant, emotional, and inferior to other members, therefore isolating himself from his family.

P (4): "But it's also hard for me, cause it's like she doesn't know what I go through every day. It becomes very emotional. She doesn't have to go through all the things I go through, cause she's normal... being me, I have to go through all the pain... I prefer to be on my own.

'Family sees me as "useless'

Four research participants expressed that they feel that their families see them as "useless" and as a helpless victim that cannot engage in occupations. Participant (4)

indicated in his quote below that he feels as if his parents consider him useless, and when he requests to go out with friends, his mother mentions his inabilities and their feelings surrounding his perceived inability to engage. This further exacerbates his exclusion and lack of support that he experiences daily, limiting his occupational choices and participation.

P (4): "My parents worry too much about me. They keep on thinking of things that might happen. The most specific thing that they say when I want to go somewhere the most specific thing that they say when I want to go somewhere with them is, who's going to help you when you need the bathroom. That is the question they ask. Every time I want to go. ... they feel that [their] child is useless".

Various participants expressed similar feelings, although their parents have not outright said these statements to the high functioning, late adolescents, with CP, as seen in the quote by P (3) below. P (4) highlighted that his grandmother had outright called him useless which caused the adolescent to self-harm. Consequences of the association with the term 'useless', are associated with a lack of independence within their lives. This often leads the adolescent with disabilities to feel sadness and a lack of support within their lives, further exacerbating feelings of exclusion and inferiority.

P (3): It feels like [my dad thinks] maybe his son is useless or something, I don't know.
P (4): "Actually… she…she said I was useless. It made me not want to be around anymore, the worst was probably when I tried to cut myself… that was basically the worst time of my life."

"Everything is my fault"

Five research participants expressed that they felt as if their families indicated stigma and blame for their disability on the adolescent with CP. It has been found in the study that research participants felt that their families have a lack of understanding surrounding their disabilities and associated impairments, leading families to believe that disabled people are considered dependent, and their families showed a lack of understanding surrounding the cause of their disability.

Research participants often felt that their families blame them for their disability and impairments, leading to feelings of guilt and therefore a lack of support leading the adolescent to feel inferior within the family, further exacerbating their exclusion, especially within family occupations This is seen in verbatim below where P (7) stated that her mother often blames her for her disability, especially during disagreements.

P (7): "My mom she say to me that …I'm making myself with this hand, it's me that do like this. And then I said – It's not me who did this hand to be like this. It's God who made me like that. And then, my heart was so sore."

A research participant revealed a different view to the others, where he highlighted cultural and supernatural causes, such as black magic used to cause harm. Participant (10) indicated that his family has blamed his disability on community members who have wanted to cause harm to his family. The 'curse' was originally meant for his mother however since his mother was pregnant at the time, he was affected by the curse rather than his mother. This impacts his family allowing him into the community, due to feelings of fear and the need to keep the adolescent safe due to his perceived dependence on others.

P (10): "…that lady was fighting for my father, and my mother said no, you can't. And then they do this magic for my mother. Stroke. My mother told me, they say magic, this talk must not come to me, must go to my mom."

In this category, barriers such as family stigma, blame, and guilt surrounding disability, with associated decreased family support was highlighted as pertinent barriers to participation in occupations. These factors lead to decreased family support, feelings of inferiority, and a result, further exclusion from important family and community occupations.

4.5.2. **Community Stigma**

Community stigma has sub-categories, namely bullying by peers, judgement by community members, and decreased socialisation.

Ten research participants expressed that preconceived judgement of their disability by community members as well as bullying by peers prevents them from participating in activities which the adolescent with CP needs and wants to perform, often leading to isolation. The isolation often poses a barrier to the adolescents' occupational participation and occupational choices. Within this category are two subcategories: judgement by community members and bullying by peers.

4.5.2.1 **Bullying by peers**

"The bullying doesn't stop..."

Ten research participants indicated that they have/are currently being bullied by members of the community. The bullying often leads to feelings of inferiority and not

being good enough, and at times feeling like a joke, which is described by P (9) below. Adolescents with CP tend to isolate themselves, to keep themselves safe, as described verbatim by P (7) below impacting negatively on their occupational choices.

P (7): "… when I... I go with them they always bully me; they always laugh at me. I don't know why and then I don't want to sit with them. Sometimes I sit with my mother. Yes. Or alone at home because I can't… I don't feel comfortable with them."

P (9): "a lot of people make fun of me…yeah most of them…they make joke, like a joke around me…my childhood was pretty rough."

Participant (4) expressed verbatim below, that he finds it difficult to retaliate when he is bullied or hears people talking about his disability in public, due to associated difficulties with movement and physical ability. This lack of movement and functionality once again leads to feelings of inferiority, especially when constantly being reminded of their disability and impairments, therefore it is only natural to want to exclude themselves from socialising. Bullying has been considered as a barrier to the occupational choices of adolescents with CP.

P (4): "It's kind of hard for you to fight back, the only thing you have, the only thing you can fight back with is verbally. So, you can't actually do anything about it. Even when you go to the teacher, the bullying won't stop because the teacher is just going to give the kid another reason to bully you. I act so big. I put up this front of being big, and nothing hurts me, but it gets hard."

All the research participants recalled experiences of being bullied by peers and/or were purposefully excluded and isolated by their group of peers, leading to feelings of inferiority with an associated decrease in their occupational choices. Participant (9) indicated that he felt that the bullying is constant and unavoidable as seen in the quote below. Participant (4) quoted below highlights that he feels that his peers think of him as not normal and cast him aside. Adolescents with CP tend to isolate themselves as a protective mechanism, impacting negatively their occupational choices.

P (9): "the bullying doesn't stop…they always bully you".

P (4): Cause, like. I'm different from the other kids, so they take it as this weird child… people think that's not normal, so they just keep me aside, don't hang around him and stuff."

4.5.2.2 **Isolated by group of friends causing social isolation**

Three female research participants expressed that they felt that they had been purposefully excluded by their group of 'friends' impacting their self-confidence, further

exacerbating their social isolation, and finally, impacting their occupational choices. This is seen in the quotes below by P (2) and P (6) where they revealed feelings of inferiority and their experiences with exclusion by their peers.

P (2): "…just leave me out. And that just felt, I felt cast out, because I felt like I was just there and no one is getting along with me, and no one is talking to me. And I'm just quiet, and I don't feel, I just feel uncomfortable. The things they were talking about, I don't know. And also, I have to go to a psychologist to speak about it with them, and I just felt so cast out."

P (6): "I did have an experience at that school, during the initial years where I had a big group of friends, and they gradually isolated me out of the group, so that led to me becoming more a-social "

Eleven (11) research participants reflected on their personal experiences regarding preconceived judgement by community members, as seen in the quote by P (1) below, where he expressed judgement regarding his wheelchair that he uses to assist him within the community. Negative judgements as described below lead adolescents with CP to feel that they are judged by what they look like and often felt misunderstood, underestimated, and seen as intellectually inferior. This community stigma and judgement impacts an adolescent with CP's self-esteem and, socialisation within the community, as an attempt to keep themselves safe, which decreases their occupational participation in available occupational choices.

P (1): "…they think I'm stupid and dumb, because of my wheelchair…just because I'm in a wheelchair, they are too quick to judge, especially my age group."

"I am judged by what I look like rather than who I am"

Four research participants revealed that they felt that they were being judged by what they looked like, and their use of assistive devices rather than who they are. This is seen in the quote above and below by P (1). Participants further felt that community members do not take the time to get to know their personalities and positive attributes, being seen as inferior and as an individual who cannot engage, which leads to a barrier to social participation and an increase in exclusion from occupations, impacting on their occupational choices.

P (1): "They do know me, but they don't know the inside of me. They think I don't know anything. They think that I'm stupid or dumb. Because [of] my wheelchair. They are too quick to judge "

"They do not understand me, they are normal"

Four research participants expressed that their needs and wants are not fully understood by non-disabled people. Participant (4) in the quote below expresses the difficulty associated with dealing with his emotions, due to being misunderstood by immediate members of his family and the community.

P (4) "…But it's also hard for me, cause it's like she doesn't know what I go through every day. It becomes very emotional. She doesn't have to go through all the things I go through, ***cause she's normal."***

The verbatim below by P (4) expresses that he feels as if members of his family and community are not understanding his needs. Adolescents with CP want to be understood and catered for their needs, whilst decreasing limitations for occupational participation and occupational choice appropriately. Research participants feel as if that they are considered as 'less human' and important enough to be understood, and are judged harshly, leading to further exclusion and isolation, impacting negatively on their occupational choices and opportunities to engage.

P (4): "People can be more understanding…People think that people with disabilities get things easy because of their disability, and people feel sad for them. And they get things all out of pity, so yeah that's what I would change. People need to be more willing to learn. Be more understanding of people. Cause, our lives aren't that easy, and we don't expect you to think they are. We would also wish to do it ourselves. You might hate it, but I wish I was you. People are not understanding… they don't understand me."

"Community members stare and make negative comments"

Nine research participants recalled negative experiences surrounding their disability, including teasing, and staring from community members, as seen in the quote below by P (9) and P (1).

P (9): "People always have things to say, they are never out of topics…"

*P (1): "*They'll look at me ... *they think I'm a ghost or something…that's why I don't go to church".*

The staring and negative comments that the adolescents with CP have reported that they constantly endure impacted their willingness to participate in community events. Participant (9) in the quote below, expressed that he felt that he was constantly spoken about within his community, especially due to his disability and inabilities.

P (9): "…like when I'm walking in the streets, they look at you like, and I'm like… for me it's uncomfortable. They're like talking about you, about your disability."

Five out of the initial nine research participants indicated that they would rather stay at home isolated than putting themselves in a situation that impacts negatively on their self-esteem, as seen in the quote by P (1) below. These negative experiences within the community lead to a negative impact on their self-esteem, feelings of inferiority, and that they are being judged prematurely, impacting on their ability to participate fully within the community.

P (1) "…sometimes I feel like I don't want to be watched, they watch you. They [also] push you in the wheelchair, I get very annoyed…and I slap the person. Sometimes I ask myself – can I go outside. I'm sitting at home, doing nothing Juffrou. It hurts me..."

Community stigma emerged as a barrier that impacts the occupational choices of high functioning late adolescents with CP. Bullying by their peers as well as preconceived judgement by community members, impacted on the participants' self-esteem and their willingness to engage. Many research participants resorted to self-exclusion to avoid negative comments and taunts from others in the community.

4.6 **RIGHT NOW, I AM GETTING NO AIR** (***Social Isolation***)

All research participants expressed that they have and/are currently experiencing social isolation and lack of familial finances. Decreased socialisation and lack of participation within the community impacts negatively on the adolescents with CP's ability to improve and practice their social skills due to a decrease in opportunities, as seen verbatim below by P (6).

P (6): "I think having a disability in itself…changes the way you do things and the way you perceive things because you have more problems socially than any other normal child would."

Many research participants indicated that they find socialisation very challenging due to their decreased social skills and would rather avoid social interactions and situations further decreasing their opportunities for socialisation and as a result, impacting negatively their occupational choices.

4.6.1 **Decreased Socialisation**

Eleven (11) research participants commented on their avoidance of social situations and as a result, decreased socialisation with family, peers, and members of the community, which factors negatively into their occupational choices. Participants further experience feelings of inferiority, questioning whether they are good enough and if it is 'normal' to have friends, increasing isolation and impacting negatively on their occupational choices. This is seen verbatim below by P (1) where he expresses the extent of his exclusion with peers and within the community.

P (1) "I'm usually I'm alone… I just sit and watch others. I'm used to it by now…Basically I do nothing".

"Socialisation can be challenging/ Decreased social skills"

Seven research participants felt that they struggled socialising with both, disabled and non-disabled peers. This can be attributed to a lack of experience in social situations due to consistent isolation, impacting the development of social skills. This is seen verbatim by P (2) below.

P (2): "It's just the purpose is to socialise. It is very hard to communicate with people and tell them what your ideas are, 'cause I'm scared they might reject it or something."

This further impacts the adolescent with CP's concept of themselves and others. Weakness in social skills may lead to feelings of inferiority and a lack of competence within this sphere, which further excludes the adolescent with CP, impacting the occupational choices of an adolescent with CP. Participant (4) expresses the difficulties which he experiences below.

P (4) "…Well socially I'm facing a lot of difficulties, because, you know, my sexuality, and finding out who I am. Cause, yea. And academically, it's just school telling you things, and with the teachers. And learning and trying to be on my own."

"Avoidance of social situations"

Eight research participants responded that they would usually avoid social situations. Reasons for their avoidance vary from enjoying their personal space, as seen in quotes by P (6) and P (1) below to not leaving the house to prevent bullying and teasing from non-disabled peers and community members, as seen in the quotes by P (6) below.

P (6) …" I keep my privacy by not interacting with others".

P *(1) "I think I'm okay being alone.…"*

P (7): "I'd rather sit at home than be bullied by others."

This shows a lack of confidence in the attitudes of the community and peers, often feelings of inferiority, and that they are different due to the constant reminder of their disability. This further isolates the adolescent with CP, impacting negatively their occupational choices.

"I'm alone and do not have any friends"

Five research participants expressed that they felt alone and do not have many peers who they can refer to as 'friends', as seen in the quote by P (7) below. This has a negative impact on their self-esteem, feelings of acceptance and inclusion as well as their competence in their abilities, affecting their occupational choices. This limits opportunities for socialisation with peers. This is seen verbatim by P (4) below.

P (7): "I don't have any friends. I'm alone. Because where I stay, when I go with them, they always bully me, they always laugh at me. I don't know why. I don't feel comfortable with them."

P (4): I think basically we don't go out as much. And if you don't go out as much …so I basically have no friends, I'm facing school the whole day, or facing my books the whole day. I don't have any friends."

Social isolation has been identified as a pertinent barrier that impacts the occupational choices of high functioning late adolescents with CP. Factors that contribute to their social isolation have been identified as difficulties with socialisation, as well as wanting to avoid social situations due to stigma, as well as a lack of social skills due to a lack of opportunities to practice socialisation.

4.6.2 Lack of Familial Finances

Eight research participants stated that their finances or lack thereof have a negative impact on their opportunities for physical participation in activities as well as accessing social media. Participants further described that socialisation and leaving the house is often expensive, needing money that they do not currently have. This has been described verbatim by P (1) below.

P (1): "I can't go to the mall… there's no money. Cause' I want to go there and use the Wi-Fi. I must put data in order to do things. It's because of no money".

Participant (1) further explained in the quote below, that finances are important, but money and love do not correlate positively.

P (1): "Getting money is important…but you can have all the billions in the world, but you can't buy love."

Participant (1) further explains that he does not like his living situation and sharing a room with his mother due to not having enough space in his home for his own room. Participant (1) has described his living situation as living in a "shack". Independence and space needed away from parents are often needed and wanted during this life stage of adolescence. This impacts on the occupational choices which the adolescent with CP has available and affordable to him/her.

P (1): "I sleep in my mom's room. I have to make it mine, I put a TV in there…But there's no money. I'm just there. I just live. If I had the money or something, I wouldn't live there."

"No money for social media and socialisation"

Five research participants brought up finances as being a pertinent barrier to their participation in activities as well as a barrier to the opportunities which they have available to them.

Participant (1) described in the quote below that he is unable to visit the main socialisation point with his peers, the mall. The lack of funds further isolates the adolescent with CP, limiting his occupational choices.

P (1): "…can't go to the mall with friends…there's no money."

Three research participants expressed that they are unable to afford network and data costs, which limits their participation on social media, such as Facebook and WhatsApp, as seen in the quote by P (1) and P (2) below.

P (1) "There's always no money… No money for WIFI or data to go on social media".

P (2): "Sometimes it's like the TV is boring, sometimes running out of ideas, and the phone is also boring sometimes. I don't have WIFI or data to go on social media. I get bored."

This lack of funds needed to purchase airtime and data to access social media further isolates the adolescent with CP, as he/she are unable to contact peers as well as access others outside of the community, such as online support groups. This lack of funds leads to further isolation impacting and limiting the adolescent with CP's occupational choices negatively.

Research participants have identified a lack of finances as a barrier to their occupational choices and participation. The lack of funds has been identified as negatively impacting their ability to attend social gatherings, as well as keep in contact

with others through technology, as data and airtime costs have been identified as unaffordable. These further decrease direct and indirect socialisation, increasing isolation for the adolescent with CP.

4.6.3 Dependence on Others

Eight research participants identified that their disability and dependence on others limit their participation in activities that the adolescent with CP need and want to perform. This dependence on others often leads to feelings of a lack of competence in their abilities, linking with feelings of inferiority which further isolates the adolescent with CP, as seen in the quote by P (4) below. This impacts negatively on the adolescent with CP's occupational choices.

P (4): "I'm not going to lie, sometimes I wake up feeling very emotional, because I have to ask for help with every single little thing. And whenever I have to ask someone for help to go to the bathroom, you lose your dignity... What is my youth?"

4.6.4 My Disability Limits Me

Ten research participants revealed that their biggest limitation is their disability and the impact that it has on the performance of activities that the adolescent with CP needs and wants to perform. Viewing their disability as their biggest limitation links with feelings of inferiority and a lack of competence and confidence in their abilities, impacting negatively on their occupational choices. The impact that their disability has on their life is seen by P (4), P (6) and P (9) verbatim below.

P (4): "Have cerebral palsy, so what can I do about it? Cause I can't go outside. I can't do anything, so…just sit in boredom."

P (6): "I think having a disability in itself causes, you know, it changes the way you do things, and the way you perceive things. It's hard."

P (9): "I don't know. I feel like it is stopping me or something like that. Holding me back most of the time. (Because when I was growing up, a lot of people used to look at me, like, weirdly, you know? My disability has affected me my whole life…"

"I'm tired of asking for help (so I don't)"

Three research participants reported that they would rather do without or not perform activities that the adolescent with CP finds difficult or needs assistance to perform.

Participant (4) indicated verbatim below that he is tired of asking people to assist with performing tasks, due to the limitations which are associated with his disability. Loss of dignity is expressed by P (4) below, due to their dependence and decreased competence in performing activities at an acceptable standard, limits their occupational choices as the adolescent chooses to isolate themselves and do without.

P (4): "I'm tired of asking people to keep helping me" …you have to ask for help for every single thing you lose your dignity."

"My disability depicts what I can do and stops me from doing what I want"

Eight research participants identified that their biggest limitation that they are currently experiencing and impacting on their occupational performance is their disability and its associated impairments. This further depicts the activities which they can and are allowed to perform, based on their feelings of confidence and competence. This lack of control of their abilities is seen verbatim by P (10) below.

P (10): "If I want to go, my body can control me too many. If I want to go like straight, my body control me to go like left … And I don't want to go left, I want to go straight."

Adolescents with CP tend to avoid performing activities which they want to perform but need assistance due to their impairments. Feelings of inferiority are evident in the verbatim quote by P (4) and P (3) below, which impacts their occupational choices negatively.

P (4): "I feel as if, if I can't do this, then I can't do that, and if I can't do this, then I can't do that … so I exclude myself, I keep in my own mind."

P (3): "It's affected me, my whole live…My disability stops me from doing what I want."

Participant (4) described below that his lack of independence in basic self-care tasks such as toileting, is a barrier to his attendance to social gatherings and independent outings into the community, such as to a mall. This increased dependence is noted to impact the participants' dignity and feelings of competence, negatively influencing and limiting their occupational choices.

P (4): "…my parents ask [me], "who is going to help you when you need the toilet… It's true!"

CONCLUSION TO THEME 2: To Explore the Barriers that Impact on the Occupational Choices of High Functioning Late Adolescents with CP

Cerebral Palsy is a movement disorder, which impacts the occupational performance of activities that adolescents want and need to perform. Participants conveyed that their

disability limits and often stops them from participating in their chosen occupational activities, limiting opportunities for engagement and skill development. Participants' have identified that their disability has been identified as increasing their vulnerability, due to their inability to perform personal tasks such as bathing and dressing independently, highlighting their needed dependence on others for assistance, impacting negatively on their self-esteem and confidence leading to further exclusion.

4.7 THEME 3: I AM NOT SAFE (*Vulnerability*)

The research question for this objective is: what are the barriers that impact the occupational choices of high functioning late adolescents with CP as seen in Table 4.4 below. The category contributing to this theme is contextual factors whereas the sub-category relates to the environment not being safe.

Table 4.4: To Explore the Barriers that Impact on the Occupational Choices of high-Functioning Adolescents with CP (n=12)

Theme	Categories	Sub-categories	Codes
I am not safe *(Vulnerability)*	**Contextual factors**	**My environment is not safe**	**It is not safe and I am scared.** I'm scared of robbers the area is ghetto I get scared, they had a gun To be honest, I don't like going outside, it's unsafe The crime, you must be back before 5 pm They wait for you with a gun
			I don't trust them I have learnt not to trust anyone They want to steal from me I have a girlfriend, but I don't trust her I used to have friends until those people stole from me and didn't come back Even my family members… I don't trust them I don't trust so many people

Participants conveyed feelings and concepts surrounding their experiences of vulnerability and a lack of trust in the people who reside and school within their immediate environments. These contributing factors cause high functioning late adolescents with CP to feel inferior, unsafe and therefore exclude themselves to keep safe from harm and violence. This fear and associated vulnerability impact negatively on the occupational choices of high functioning late adolescents with CP.

4.7.1 Contextual Factors

Seven research participants expressed that contextual factors, such as within their immediate environments and experiences with people in their families, peers, and

communities posed barriers to their occupational choices and participation. This is seen verbatim by P (12) below, where he highlights his fears of leaving his home due to feelings of being unsafe.

P (12): "To be honest, I don't like going outside, it's unsafe. Friends put you on the bad side, they smoke so I don't want to go back to the other life…yeah, they're not good for me,"

Research participants, as seen verbatim by P (12) above, highlighted their vulnerability due to their disability, emphasising their fears surrounding their occupational participation in activities at home and within their community, negatively impacting their occupational choices.

4.7.2 "**My Environment is not Safe**"

Six research participants indicated that their home and school environments have aspects that they consider to be barriers to their occupational participation. These contextual factors lead the adolescent with CP to feel unsafe as they are unable to move about freely and protect themselves therefore excluding and isolating themselves to keep safe, negatively impacting and limiting their occupational choices.

"It's not safe and I'm scared"

Participants conveyed feelings of fear as well as the associated lack of trust due to their perceived and actual vulnerability. This is seen in the quote by P (1) below, where he recalls the strict measures that he and his family have put in place to ensure that the adolescent with CP is safe.

P (1): "The area is ghetto… The crime, you must be back before 5 pm. They wait for you with a gun…I get scared".

Reasons stem from the perception that people with disabilities are vulnerable, easy targets, and are unable to protect themselves or remove themselves from dangerous situations. These contextual factors limit the occupational choices for the adolescent with CP.

"I don't trust them"

Eight research participants expressed that they do not trust others within their family, school, and community environments. This is seen in the quote below by P (1).

P (1): "…I have learnt not to trust anyone…"

Reasons for this strong emotion stems from previous negative experiences where others have attempted to take advantage and steal from the adolescent with CP, leading them to isolate themselves to keep safe. This can be seen in the quote by P (1) below, where he highlights his experiences with friends and within the community.
P (1): "I used to have friends until those people stole from me… and didn't come back".

This absence of trust in family, friends and community members with associated isolation is used by participants as a preventative measure to keep themselves safe (physically and emotionally). This personal preventative measure impacts negatively on their occupational choices and participation. Participant (1) highlights verbatim below the extent that the participant feels unsafe and vulnerable, that he admits that he does not trust anyone in his life, not even his family members.
P (1) "I have learned not to trust anyone…even my family members, I do not trust them".

CONCLUSION TO THEME 3: TO EXPLORE THE BARRIERS THAT IMPACT ON THE OCCUPATIONAL CHOICES OF HIGH-FUNCTIONING ADOLESCENTS WITH CP

Participants revealed feelings of vulnerability, which has emerged as a major barrier to the occupational choices of high functioning late adolescents with CP. Contextual factors such as family, peers, and community environments were brought up as main barriers, impacting negatively on the participants' feelings of safety and trust in others, leading to further exclusion of themselves within their social environments.

4.6 SUMMARY OF FINDINGS

This chapter described the findings of the facilitators and barriers that impacted the occupational choices of high functioning late adolescents with CP within Gauteng, SA. The three main themes which emerged and were described in this chapter; inclusion in life's decisions and occupational choices which are related as a facilitator. Feelings of inferiority and vulnerability, related strongly to the barriers which adolescents with CP currently experience, impacting on the occupational choices of high functioning late adolescents with CP.

CHAPTER 5

5. DISCUSSION

5.1 INTRODUCTION TO DISCUSSION

In this chapter, the researcher discusses the factors which emerged that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with CP in Gauteng, SA. Within this chapter each theme is discussed separately, opening with the facilitators which emerged being the importance of inclusion in life's decisions and occupational choices. Concluding within this chapter are the barriers which emerged, being feelings of inferiority and decreased safety.

The purpose of the study was to explore the facilitators and barriers that impact the occupational choices of high functioning late adolescents with CP, within Gauteng, SA. Facilitators which emerged from the study will be suggested and encouraged as pertinent for participation in activities that high functioning late adolescents with CP want and need to do, impacting positively on their occupational choices.

Barriers that emerged could be used to educate participants, parents, teachers, and health care professionals surrounding the difficulties which are experienced, so that we can minimise these barriers to ensure that the adolescent with CP's participation is positive. Enhancing facilitators whilst decreasing barriers will assist in high functioning late adolescents with CP to meet Havighurst's (1972) age-typical developmental tasks, increasing functionality (Havighurst, 1972; Manning, 2002).

Theme 1: Inclusion in life's decisions and occupational choices

Theme 1 addressed the first objective of this study, namely: "what are the facilitators that impact on the occupational choices of adolescents with CP? Theme 1 discussed the importance of being included in making in life's decisions and occupational choices, and not just be accommodated for by their parents, teacher, and society. Two categories are discussed within this theme: familial resources and finances, concluding with the importance of attending a school for learners with special needs as it caters to many of their needs and limitations associated with their disability. It is necessary to listen to and engage children with disabilities

Participants believed that it is important to do things with their families by going out, spending time with the family, or being together at home. Participants further felt that

playing on the phone, video games and iPad are important things to do. By attending a school for learners with special needs that cater to individuals with disabilities, participants felt normal and accepted as they are surrounded by people who have similar needs as them. They further felt that school accommodates them, fulfils their needs, and makes their life more bearable. Participants also stated that sport is important to them and they get the satisfaction of accomplishment when representing their school for sports and by getting the opportunity to compete and sometimes win. Sport also offers sensory experiences of pleasure (through physical activity) as well as an important aspect of experiencing and participating in occupations as an occupational being.

Occupational participation is seen as an important determination for quality of life in the lives of an adolescent with CP (Badia, Longo, Orgaz, & Gómez-Vela, 2013). Participants in this current study want to be included in their lives' decisions and choices, and not just accommodated for, participants felt that it is within their rights to be included. Adolescents with CP are not included therefore felt that their rights are thus violated (South African Human Rights Commission, 2018).

5.1.1 Familial Resources and Finances

Family dynamics are important. A quarter of the research participants indicated that they like to spend time, play sports, or go on outings with their families. Feeling safe and experiencing close personal relationships with members of their family is noted as facilitators to occupational participation, with feelings of acceptance within their families.

Adolescents with CP will therefore have the confidence that their trusted family members will protect and support them within the community (Robinson, Graham, Fisher, Meltzer, Blaxland, & Johnson, 2018). Families must however have the resources and finances to support this participation. There is an association between participation in life situations of adolescents with CP and their environment (physical, social, and attitudinal) which can either be a barrier or a facilitator to occupational participation (Colver et al., 2012). Parents, within their social and positive financial situations, facilitate participation within family and community positively, increasing adolescents with disabilities' quality of life.

If a child receives positive support from the family, it is beneficial to the younger child whilst growing up. As the child gets older, other people within the environment and

community start to play a more important role. This is also the time when a child with CP tends to experience an increase in negative factors such as fear and therefore decreased motivation. This increase in fear has been noted in many of the participants of this current study, especially within families who offer poor support to the individual with a disability (Bloemen, Takken, Wittink, Benner, Mollema & De Groot, 2015; Clemente, 2017).

Bloemen et al., (2015) and Clemente (2017) accentuate the need for adequate facilities, and adequate support, adapted equipment, accessible transport, and general accessibility for adolescents with CP. This sentiment is supported by the findings of this study as adapted sports being offered by the school for learners with special needs, includes having adequate support from teachers, coaches, and family members. Participants from this study enjoy competing with others with similar abilities and disabilities as well as offering adequately adapted equipment facilitating participation within sports, increasing the individuals' skill set and self-esteem positively (Bloemen et al., 2015; Clemente, 2017).

5.1.1.1 **Use of technology**

The use and affordance of technology are important for an adolescent with CP. This relates to playing on the phone, video games, and utilising an iPad, otherwise called mobile applications. Adolescents are extremely interested in technology as their interest is stimulated through novelty and technology (James, Ziviani, King, & Boyd, 2016). They like staying 'connected'. This applies to most adolescents, both disabled and non-disabled.

The benefits of video games and mobile applications are that it provides the child with social, cognitive, and emotional skills, especially when communicating with others online (Granic, Lobel, & Engels, 2014). Participants from this study enjoyed exploring the internet, video games, and participating in other mobile applications, as long as the participant can afford the costs associated with the technology (Granic et al., 2014). This sentiment is echoed by the Organisation for Economic Co-operation and Development (OECD, 2019). The use and affordance of technology have been brought up as facilitators in the current study, as they feel less isolated and more connected to their peers.

When an adolescent with CP uses an iPad, it can offer opportunities to enhance learning, absorb information, aid communication, and give emotional support.

Technology enhances occupational performance for adolescents with disabilities, which offers a sense of competence and influences their occupational identity, utilising the integration of technology into different spheres of the adolescents' life. This is important, also because of being affordable, unlike other assistive devices that need adjustments or are difficult to acquire such as speech synthesisers. Children with CP tend to master iPads quite easily (Khoo, 2016).

5.1.2 Attending a School for Learners with Special Needs

The importance of attending a school for learners with special needs cannot be underestimated, as mentioned by all the research participants from this study. Special education is the design and delivery of teaching and learning strategies for individuals with disabilities or learning difficulties who may or may not be enrolled in regular schools. Children who require special education have disabilities that affect them in various ways (UNICEF, 2013).

A sense of belonging has strong links with the human condition of spirituality. Belonging is the degree to which a child in a school for learners with special needs feels he/she is included and being supported in different social settings, which corresponds with the current findings of the study as participants conveyed views of acceptance and inclusion within the school environment. Students with disabilities must be in a school with a positive climate, nurturing their special needs and skills (Pesonen, 2016).

Special education is education that specifically caters to the unique needs of a learner with a disability, such as an adapted curriculum (Pullen & Hallahan, 2015). This means that the individual with a disability will receive individualised education according to their needs. It is significant as they require extra support and intervention to overcome their challenges due to their disability. Weicker (2012) found that students with a disability who attend a 'normal' school lack academic confidence and self-esteem.

If a learner is placed in a special education institution, students will have an increased chance of academic and social success (Weicker, 2012). All research participants from the current study indicated that they feel more normal and accepted in a school for learners with special needs as they are surrounded by people like themselves. Other research participants from the current study suggested that they get additional support, and their needs are being met. It also makes their life more bearable.

Participation in sport was described as life-changing, along with feelings of accomplishment. The learner in school for learners with special needs receives more attention and instruction and is happy (Wang, 2009).

5.1.2.1 **Participation in sports**

Adolescents have the want and need to participate in a sport which results in enhancing psychological well-being as it can provide the opportunity to form new friendships, help them to express their creativity, improve their sense of well-being, self-image, identity, and promotes purpose in their life. This sentiment is echoed within the current study where participants conveyed feelings of success, increased self-esteem, and feelings of competence correlating with their participation within sports (Adolfsson, Malmqvist, Pless, & Granuld, 2011; Badia et al., 2013).

When adolescents with CP participate in sport, they reported a sense of achievement and self-confidence. In agreement with the findings of the study, participation in sports can have positive effects (Bloemen et al., 2015; Clemente, 2017). However, Clemente (2017) stated that one must consider the lack of gross motor development and poor cardiovascular fitness, which can hinder an individual in sports (Clemente, 2017).

On a positive note, if an adolescent with CP can participate more regularly, this will lead to improvement in psychological well-being, increase in skills and self-esteem, reduce cardiometabolic risk, lead to healthier body size, therefore increasing socialization, decreasing occupational alienation from the family and society and therefore increasing occupational performance positively (Boddy, Downs, Knowles & Fairclough, 2015).

Constraints regarding participation in sports are large teams if the individual is not being allowed to participate, if there is a long waiting list, and if the sport grounds are too uneven affecting mobility (Bloemen et al., 2015). These authors also mentioned that fundamental movement skills might be personal requirements that might hinder an adolescent from participating in sports, therefore posing as a possible barrier to occupational choices and occupational performance (Bloemen et al., 2015).

CONCLUSION TO DISCUSSION

There are two variants that one needs to understand, namely facilitators and barriers. Negative environments can hinder a positive environment are when family, teachers,

peers, and other people hinder physical activities, or if there is a lack of support, or being bullied.

On the other hand, if an adolescent gets adequate support, makes friends, or experiences positive attitudes from family, peers, teachers, their results are positive. This is especially important when participating in physical activities or sports, as supported by the results of this study (Bloemen et al., 2015). Literature states that there is limited participation in physical activities in adolescents with disabilities and highlight the need for addressing the barriers and limitations (Clemente, 2017).

This emphasises the need for adapted sports programmes which are often offered within special schooling. This corresponds with the findings of the study as participants often spoke positively surrounding their participation within the adapted sports available to them. Other restraints and barriers identified are lack of knowledge regarding where to train, equipment that may be too expensive may further hinder the adolescent with CP (Bloemen et al., 2015).

5.2 THEME 3: I AM NOT SAFE

This theme explored the 'barriers that impact on the occupational choices of high-functioning adolescents with CP'. In this study, contextual factors have been identified by high functioning late adolescents with CP, especially relating to the environment, discussing their fears, and lack of trust in people within their lives. According to the African Charter on the Rights and Welfare of the Child states that a child with a disability such as CP should have the right to special measures in terms of protecting so that they can participate actively within the community. this theme will describe the reasons that high functioning adolescents with CP feel that they are unsafe participating within activities (Organization of African Unity, 1990).

5.2.1 Contextual Factors

Compromised and limited issues surrounding safety and health are barriers associated with adolescents with CP and problems that they face because of their disability, as discussed by Clemente (2017). Moreover, Higgins (2010) found that any type or form of disability contributes to a higher risk of assault and victimisation. This compared well with the findings reported by participants of this study as the findings revealed that the participants are often victimised by members of the community and peers and often seen as an 'easy target' (Higgins, 2010; New Zealand Statistics, 2014). There are many reported psychological effects of being bullied, be it direct or indirect bullying. The findings of the current study show that the effects of victimisation have serious and long-term effects on the individual, impacting on aspects of Havighurst's (1972) developmental milestones such as trusting others in their environments, often seen in difficulties in accepting themselves, achievement of independence, achieving new and more mature relations as well as preparation for marriage and family (Tentoglou, 2001; Havighurst, 1972).

The importance of personal safety has been described by participants in a study conducted within the Southern Cross University (2018), concepts such as being in a safe place out of danger and absence of maltreatment emerged as pertinent factors for participation (Robinson, 2020). Feeling emotionally safe was an additional description from the above-mentioned study, where participants responded that being around trusted individuals, being comfortable, understood, respected, and protected were facilitators to their safety. Many participants of the study revealed concepts surrounding the above descriptions from past studies such as a lack of trust of many people within their lives. Participants from the current study highlighted that they do not feel safe

leaving the house due to fears of maltreatment by peers and community members, therefore, exacerbating social isolation (Robinson et al., 2018).

Individuals with disabilities who are or have been bullied, presented with concentration difficulties and anxiety. This resulted in them not wanting to leave the house to keep themselves safe reporting skipping school without their parents' permission (Tentoglou, 2001).

Victims have generally been found to have a lower level of peer acceptance, their perception of self and others, which directly impacts on meeting Havighurst's (1972) developmental milestones appropriately. Many of the past studies conducted over the past 20 years have found that individuals with physical disabilities are easy targets for victimisation (Dawkins, 1996; Hassed, Hendon, & Cunniff, 1996; Yude, Goodman, & McConachie, 1998; Havighurst,1972). The findings from these studies correlate with the findings of this study, where participants expressed their experiences with victimisation proving that very little has changed in the past 20 years due to the unchanging community stigma.

Participants of the current study indicated that they do not feel safe, felt scared to leave the house, and not being able to trust everyone. This correlated with the study conducted in New Zealand (2014), where disabled individuals reported that they were less likely to go out in the community whilst it is dark, and they are alone, due to fear of safety (New Zealand Statistics, 2014). Although this study was conducted in New Zealand, a minority-world country, participants of the current study concurred with their reports on feeling decreased trust and safety within their communities.

A participant with CP from Tentoglou (2001) study compared her victimisation to being a "cat and mouse game" where individuals with disabilities are perceived as weak therefore the disabled individual was the target aka the "mouse" while the other was the "cat" correlating with control and power exerted over the individuals with disabilities (Tentoglou, 2001).

Three domains play a role in the life of an individual with CP and their environmental context.

Ozdemir and Tezcan (2017) identified the following domains:

- Personal domain: Inner and social: refers to family structure, income level, and social opportunities, which correlates with the barriers, which were identified within the study.
- The external natural environment refers to air, water quality, quality of roads, etc. This was echoed by participants of the current study.
- The external social environmental domain refers to cultural, social, and religious institutions, schools, healthcare, security, social opportunities, and shopping. These aspects emerged as pertinent in the current study (Ozdemir & Tezcan, 2017).

This implies that individuals with CP are subjected to the same environmental domains as people without any disability or impairment. However, adolescents with CP must overcome several challenges in this regard to prove success and meet Havighurst's (1972) developmental milestones so that they may achieve success in future stages (Havighurst, 1972).

Previous literature indicates children with CP experience several challenges regarding their moods, negative emotions, lack of social acceptance. Their physical well-being, financial resources, social support, school environment and positive relationship with family and friends correlates with the sentiments expressed by participants of this current study (Robinson et al., 2018; Tentoglou, 2001).

The environmental concerns coupled with the increased level of dependency on adults for aspects such as personal care further exacerbates the risk by increasing their exposure to violent situations (Shah, Wallis, Conor, & Kiszely, 2015). Shah et al., (2017) further concluded that the risk for sexual violence and needing protection is three to four times greater when compared to their non-disabled peers, which correlates with the findings of this current study where adolescents with CP reported feeling vulnerable, unsafe, and at times have been involved in violent situations.

Research participants of both studies therefore, choose to remain indoors due to fear, impacting their skill development, social interaction as well as inclusion within the community. Reasons for this stigma within the community stems from the view where disabled individuals are inferior to their non-disabled peers (Shah et al., 2017). Their need for segregated services and dependency on others for their basic and social needs place adolescents with CP in an increasingly vulnerable situation. Individuals

with disabilities are perceived by others as “eternal children” being seen as innocent, naive, and asexual beings (East & Orchard, 2014, p. 336).

5.2.2 I Don’t Trust Others

Participants stated that their environment is not safe, are scared, and they do not trust others as they are easily targeted, judged, and seen as an easy target for crime. A study conducted by Robinson et al., (2018) found that participants in their study are often judged and experience threats from unknown people, from aggressive strangers in the community, and within public transport. Participants of the current study worried about their personal safety from people wanting to steal, rob, or abuse them physically correlating with Robinson et al., (2018) study, highlighting trust concerns. Mepham (2010) correlates a high incidence of bullying with a similarly high incidence of abuse in individuals with disabilities. Participants from both the current and Mepham (2010) study report experiences of abuse and harm leading to feelings of decreased empowerment and decreased safety which resulted in a preference to keep themselves safe by remaining at home, leading to further exclusion (Mepham, 2010).

A positive and safe environment is essential for adolescents with CP. Parkinson, Rice, and Young (2011) noted that adolescents with CP are concerned about their safety, therefore correlating with the findings of the current study. These stress the importance of teachers, family assistance, and education of these safety factors to assist adolescents with CP to face these challenges.

Another aspect that Parkinson et al., (2011) addressed is that children with CP enjoy participating in recreational activities although felt they cannot perform well, showing a decrease in self-esteem and development of skills as they were unsure about their safety and ability to participate in the absence of discrimination, limiting participation in activities that the individual wants and needs to perform (Parkinson, Rice, & Young, 2011).

Shimmell, Gorter, Jackson, Wright, and Galuppi (2013) stressed that environmental factors (physical, attitudes, and social policies) need to be considered as barriers in the life of individuals with CP, this sentiment was consistent with participants of the current study where they faced these barriers (Shimmell et al., 2013). Environmental barriers limit a person’s participation in mainstream society and community. Physical well-being has been proven to have positive benefits on an adolescent with CP, whereas negative

aspects are linked to environmental factors such as decreased accessibility, adaptations, safety, and so forth (Dahan-Oliel et al., 2012).

CONCLUSION TO THEME 2

Environmental factors involve more than just the barriers of being scared, feeling unsafe, and not trusting other people. The facilitators involve the social support of parents, school, coaches, support staff, mentors as well as role models. It also relates to family culture, time commitment, affordability, transportation, accessibility, and personal factors (self-perception, self-worth, self-esteem, and skill development) keeping up with challenges and psychosocial development and achievement of Havighurst's (1972) developmental stages (Shimmell et al., 2013; Havighurst, 1972). On the one hand, if there are environmental barriers, it has negative effects on participation, areas of service, assistance, attitudes, work, school, and policies (Stewart et al., 2012). Contrary to the above, when children and adolescents with CP are exposed to a positive and safe environment, they will be able to make informed choices, not only in the present but also in the future. This sentiment was echoed by Stewart et al., (2011).

5.3 THEME 3: AM I GOOD ENOUGH? (*Feelings of Inferiority*)

This theme aimed to answer the first research objective: *what are the barriers that impact the occupational choices of high functioning late adolescents with CP?* This study identified three categories: exclusion from family, which is associated with decreased support, and family stigma surrounding their disability. Secondly, community stigma will be discussed, highlighting preconceived judgement from community members as well as bullying by peers. Thirdly, social isolation will be discussed with resultant decreased social skills and therefore avoidance of social situations.

The theme *Am I good enough (feelings of inferiority)* was strongly supported by previous literature (Chapman, 1988; Hussian, 2006; Legodi, 2014). This current study found four categories namely: exclusion from their family, community stigma, social isolation, and the dependence on others which caused participants to feel that they are not good enough. Hussain (2006) supported the categories which emerged, both during the data collection of the current study and Hussain's (2006) personal research conducted in India. Hussain (2006) explored self-esteem in individuals with disabilities, participants displayed lower levels of self-esteem and self-worth (Hussian, 2006). This decreased self-esteem and self-worth coincides with the finding of the study, which was further supported by past studies, concluding that the impact of a disability

correlates negatively with the development and concept of self (Chapman, 1988; Cooley & Ayres, 1988; Grolnick & Ryan, 1990). Legodi (2014) found that an individual with CP, not only restricts the functioning of the individual but also restricts the development of self-image leading to a sense of inferiority, further supporting the findings of this study (Legodi, 2014). It must be noted that Johnston and Sinclair (2003) reported opposing results to the current study, finding minimal difference in self-worth when compared to their typically developing peers, depicting that the presence of a disability does not result in a lowered self-esteem and self-worth (Johnston & Sinclair, 2003).

5.3.1 Family Excludes Them

In this study, participants indicated that their daily occupations did not involve doing activities as a family and with associated exclusion from building relationships and skills. Participants further relayed experiencing a decreased family support as well as family stigma and guilt surrounding their disability. Davis, Reddihough, Murphy, Epstein, Reid, Whitehouse, Williams, Leonard and Downs (2017) concluded that social connectedness and relationships are important in social settings, especially within the family, correlating with the findings of this study as participants lack those relationships leading to decreased social connectedness and growth (Davis et al., 2006).

Olawale et al., (2013) highlight that an individual with disabilities can often be deprived of opportunities, such as recreational facilities and those that develop a positive sense of self-esteem. Olawale et al., (2013). The authors further highlighted that specifically within African communities, most families perceive a disability as a punishment from the Gods. or due to wrongful acts committed by a family member. These perceptions are especially directed towards the mother, leading to the shifting of blame and often ultimately in family and marriage breakdown, which is supportive of the findings of the current study (Olawale, Deih, & Yaadar, 2013). This decreased family support due to associated stigma will lead to a lack of social inclusion and decreased enjoyment, which leads to limitations in social maturity impacting self-worth and feelings of inferiority (Davis et al., 2017).

Research participants experienced isolation from their family, whereas they craved family time and wanted to be accepted and involved in their family's lives. Participants also revealed feelings of decreased emotional support from members of their family, which lead to feelings of inferiority and feeling unimportance. Olawale (2013) reported that her study found that half of the parents felt ashamed and embarrassed of their child with a disability, leading to the social exclusion of the individual with a disability

as stress and coping mechanism, correlating with the findings of familial exclusion within the study. She further expressed a significant decrease in the quality of life of the main caregiver including problems such as a loss of family joy, which impacted the inclusion of the individual with a disability (Olawale et al., 2013). Clemente's (2017) findings corresponded with the findings of this study, where it was suggested that being with peers, getting positive encouragement from others, and family involvement are important facilitators in the life of an individual with CP. This assists the individual to meet their developmental milestones appropriately and therefore presents an increased opportunity for success in their futures (Clemente, 2017).

Research participants in this current study feel that there is a general opinion that they will not be able to socialise, go out, or to be able to engage with other people as learnt from past experiences within their families. On the other hand, a non-supportive family includes downplaying challenges, not giving assistance, and discouraging children with CP to set high goals related to education or activities. On the other hand, if the family gives the necessary support whilst including them in family activities, decision making, and giving encouragement will lead to positive feelings of competency and development of positive attitudes and self-worth (Freeborn & Knafl, 2014).

There was a consensus in this research study that their families do not understand their problems. A study conducted by Sharkey, Lloyd, Tomlinson, Thomas, Martin, Logan, and Morris (2016) highlights the importance of the involvement of parents in the lives of individuals with disabilities. The authors stress that both the child and parent involvement is a key to success in decreasing isolation, as well as their involvement in life's decisions, which decreases feelings of inferiority and consequently increasing self-esteem and skills (Sharkey et al., 2016).

5.3.2 **Isolation from Family**

Research participants in this current study experienced isolation from their family, whereas they craved family time and wanted to be accepted and involved in their family's lives. Participants also indicated feelings of a lack of emotional support from members of their family that leads to a feeling of inferiority and feeling unimportant. Jones et al., (2018) found that adolescents with disabilities experience high rates of social isolation and stigmatisation, even within the family household. Similarly, Clemente's (2017) findings correlated with those findings of the current study. The findings of this study and suggested that being with peers, getting positive encouragement from others, and family involvement are important factors in the life of an individual with CP (Clemente, 2017). However, Blum, Resnick, Nelson and St.

Germaine's (1991) study opposes the findings of this category, depicting that participants with CP conveyed positive views with no difference of attitude noted towards both their mother and father This research study was conducted in a first world country (Blum, et al., 1991).

A quarter of the research participants also felt that their family sees them as being useless and that everything is their fault, leading to blaming themselves for their disability and associated family stresses. Schulz and Decker (1985) highlight that self-blame for their disability impacts coping skills and their ability to cope in the future, and according to this study, impacts Havighurst's (1972) developmental steps to successfully transitioning throughout life (Manning, 2002; Schulz & Decker, 1985). Tentoglou (2001) found that many individuals with disabilities have low self-esteem and negative self-attributions towards themselves and their disability and may further intensify their social inadequacy as they many feel as if they are to blame for their disability and associated occupational challenges (Tentoglou, 2001). Miller's (2007) findings correlate with the findings of this study, stating that in general, families struggle to understand the reasons for their child's disability, needing to find someone to blame, often blaming the medical system, themselves, or the child (Miller, 2007; Tentoglou, 2001).

5.3.3 **Community Stigma**

Badia et al., (2013) believed social support and feelings of competency play a role in the quality of life of those diagnosed with CP (Badia et al., (2013). Dahan-Oliel, Shikako-Thomas and Majnenemer (2019) also accentuated that participation in leisure activities and skills development will enable adolescents with CP to engage with peers and to develop friendships (Dahan-Oliel et al., 2012; Majnemer et al., 2015; Shikako-Thomas et al., 2013).

This study found that high functioning late adolescents with CP expressed that they felt decreased competency in their abilities and skills due to the lack of opportunities which are presented to the individual with a disability. These decreased opportunities are often due to community stigma and wanting to isolate due to negative comments and staring. The decreased variety and opportunities presented to the individual with a disability impacts negatively on the development of the individual, affecting the achievement of Havighurst's (1972) developmental stages leading to feelings of inferiority (Havighurst, 1972; Manning, 2002).

Badia et al., (2013) study highlighted that individuals with CP have similar needs than typically developing children regarding health, opportunity to learn skills, meaningful occupation as well as the possibility to contribute to the lives of other people (Badia et al., 2013). Wintels et al., (2018) reported that children with CP may sometimes have to cope with negative comments from others, corresponding with the findings of the study. These feelings of fear and degradation may deter children with CP from progressing within society, leading to feelings of inferiority. Authors from a different study states that children with CP want and crave to be normal, supporting the findings of this study (Wintels et al., 2018).

Makris, Dorstyn and Crettenden (2019) stated that emotional, family and social networks are positive factors that can contribute to quality of life (Makris, Dorstyn, & Crettenden, 2019). Therefore, it is important that the family must include the adolescent with CP in the family and accept him/her and their disabilities and limitations (Freeborn & Knafl, 2014). These authors also emphasised the positive effects of encouraging friendships with their siblings (Freeborn & Knafl, 2014). If an individual with CP does not have any friends or is friendly with siblings, he/she will struggle to be understood or even valued, correlating positively with the findings of the study as participants from the current study reported that doing activities with family (including siblings) was reported as a facilitator to their occupational choices (Freeborn & Knafl, 2014).

Bantjes, Swartz, Conchar and Derman (2015) reported that participants from their study often felt that they needed to deal with staring and felt that they are constantly under scrutiny. Being treated as intellectually impaired due to their movement limitations and being underestimated are reasons for wanting to socially isolate from members of the community and peers due to feelings of self-consciousness, therefore excluding themselves in order to protect themselves from those around them (Bantjes, Swartz, Conchar, & Derman, 2015).

5.3.3.1 **Bullying by peers**

Participants also expressed their dismay of bullying by peers. Badia et al., (2013) discusses the implications of decreased social support from their family and peers, which can influence their moods and emotions negatively, as participants from the current study correlates with the difficulty in dealing with their emotions (Badia et al., 2013).

Chatzitheochari, Parsons and Platt (2016) study found that there is limited evidence surrounding bullying, victimisation and childhood disability, where majority of existing research has been embedded in the medical model (remedying the disability through a medical cure) rather than integrating the social models of disability, an emphasis placed in the change in the interaction between the individual and society (Chatzitheochari, Parsons & Platt, 2016). Lindsay and McPhereson (2012) findings of their study resonates with the findings of this study, where they found that individuals with disabilities are often implicitly and explicitly bullied, leading to verbal and physical bullying which leads to social exclusion from their peers. This contributes to feeling inferior to their peers and wanting to self-isolate to keep safe (Lindsay & McPherson, 2012).

Nuri, Aldersey and Ghahari (2018) stated that apart from inaccessible environments, stigmatisation and discrimination against individuals with CP were definite factors that isolate them and their family from the mainstream society. This resonates with the findings of the study as participants from the current study reported isolation from society due to stigmatisation and discrimination (Nuri, Aldersey & Ghahari 2019). Participants from Bantjes et al., (2015) study reported that they felt as if their lives and bodies are subject to scrutiny and attention by others in the community and peers and will therefore socially isolate to protect themselves from further harm (Bantjes et al., 2015).

Carter and Spencer (2006) found that a variety of bullying tactics are being used by peers and members of the society, such as name calling, teasing, physical attacks, taking of their belongings, imitating and making fun of the individual with a disability, leading to a lack of socialisation by the individual with a disability and feelings of loneliness. These bullying tactics are equivalent with the findings of this study as participants highlighted that the experienced bullying tactics are a pertinent factor to participation within the community (Carter & Spencer, 2006).

Participants of both the current study and the study undertaken by Bantjes, Swartz, Conchar and Derman (2015) report that community perspective of being disabled is often associated with not being able to participate appropriately; is often offensive and hurtful as the association is often with decreased independence, which further isolates the individual with a disability due to preconceived perceptions of their limitations and disabilities (Bantjes et al., 2015). This decreased socialisation leads to challenges for

adolescents with CP as they want to socialise and be accepted in social circles, and they will need to develop strategies to cope with social exclusion (Wintels et al., 2018).

In conclusion, bullying is considered to be a “barrier to being” which in turn affects the adolescents’ sense of self and well-being eventually being a pertinent marker of social inequality (Chatzitheochari et al., 2016). This often leads to the individual undermining their sense of self efficacy and self-esteem, linking to feelings of inferiority, as expressed by participants of this study (Connors & Stalker, 2007). Adolescents with CP face multiple developmental and social challenges, physical limitations, poor socialisation and skills and have limited recreational activities and therefore experience stigmatisation within the community (Freeborn & Knafl, 2014).

5.3.3.2 **Right now, I am not getting any air** (***social isolation***)

For healthy development, it is necessary for social participation, leisure activities, entertainment, self-improvement, and religious activities are performed at an acceptable standard as noted by different authors such as Dahan-Oliel et al, (2012); Shikako-Thomas et al. (2013) and Stewart, Lawless, Shimmell, Palisano, Freeman, Rosenbaum, and Russell (2012). These studies correlate with the findings of the current study, where majority of participants expressed decreased participation in the categories of social participation, leisure activities, entertainment and religious activities, impacting on their ability to fully reach Havighurst’s (1972) developmental milestones appropriately (Havighurst, 1972). It is important for individuals with disabilities to participate in the above categories, to improve their skill set as well as their sense of competence, assisting in decreasing feelings of inferiority. Interacting with friends is important for a child with CP (Bloemen et al., 2015).

5.3.3.3 **Dependence on others**

Participants of the current study expressed that their disability and associated limitations as the biggest barrier that they face, correlating with the findings from Bantjes et al., (2015) study. Bantjes et al., (2015) participants related their disability and impairments to being taken care of by others and being treated as an infant as well as being perceived as powerless (Bantjes et al., 2015). These authors further found that adolescents with CP aspire to achieve independence and autonomy, which has been shown to increase their self-efficacy, self-esteem and signifies their participation regardless of their disability and subsequently ‘normality’ (Bantjes et al., 2015). These wishes which were indicated in Bantjes et al., (2015) study, which correlated with the findings of the current study as those participants who depended on others for

assistance felt that they would rather do without than ask for help as this exacerbates their vulnerability and feeling that they are a burden to their family members. Striving for independence and autonomy assists the adolescent with CP to move through Havighurst's (1972) developmental milestones, decreasing feelings of inferiority, feeling "normal" and therefore being able to master future milestones appropriately (Havighurst,1972).

Contrary to the above, Swain, French and Cameron (2003) revealed that disabled people may deny or conceal aspects of their disability and impairments in order to assist in managing the negative effects of non-disabled people regarding disabilities (Swain, French & Cameron 2003). Intrusion of privacy of the body and emotional spaces are often everyday experiences for an individual with a disability, which resonates with findings of this current study as participants revealed a lack of privacy within their home and community environments, reporting feeling loss of dignity when needing assistance, especially with ADL's (Bantjes et al., 2015).

CONCLUSION TO THEME 3

In conclusion, the barriers regarding feelings of inferiority as discussed above, are seen as definite barriers to participants being able to participate in occupations freely and of their choice. Individuals with disabilities are often categorised into a minority group, affecting the development of self-identity, which leads to developmental consequences, especially with regards to meeting Havighurst's (1972) developmental stages appropriately (Havighurst, 1972; Bantjes et al., 2015).

Regarding community participation, Milićević and Nedović (2018) concurred and stated that home and community participation is lower with individuals with CP than compared to those without CP due to the abovementioned factors, which correlated with the findings of the current study. Participants of the current study reported a lack of participation within the home and community. Milićević and Nedović (2018) found in their study that children with CP were absent from almost one-fifth of home-based and half of community-based activities, impacting negatively on inclusion and therefore feeling not good enough to be included in activities (Milićević & Nedović, 2018).

Davis et al., (2017) sums it up and states that there is a need for researchers to give more attention to the barriers, which have emerged from the study, as these barriers expressed by participants are recurring in many past studies, showing a lack of improvement within these domains. Aspects such as physical and emotional needs,

building communication skills and maintaining it with social, and community involvement is imperative (Davis et al., 2017).

Feelings of inferiority and not feeling good enough were the main barriers, which emerged as impacting the occupational choices of high functioning late adolescents. Feelings of family exclusion, community stigma and social isolation were the subcategories covered within the discussion, which were supported by previous studies and literature, showing very little evolvement from barriers previously identified in literature for this population.

Feelings of vulnerability and not feeling safe enough to participate fully in occupations that a high functioning adolescent want and need to perform have been identified by participants as a barrier to their participation. Contextual factors emerged as the main subtheme where participants expressed that their environments are not safe as well as not being able to trust others due to their perceived and actual vulnerability.

5.4 CONCLUSION OF DISCUSSION

This section focused on the facilitators which emerged during the study where participants expressed that being included in life's decisions and occupational choices positively affects their participation in occupations of ADL's. Aspects such as familial resources with associated acceptance, the usage and affordance of technology to remain connected to peers as well as the positive effects of attending a school for learners with special needs and being offered opportunities to play sports were discussed and related to relevant literature and studies. Participants in this current study want to be included in their life's decisions and choices, and not just accommodated for.

Adolescents with disabilities further feel that inclusion is a human rights issue. According to the South African Constitution where human dignity, equality and the advancement of human rights and freedom is utilised as a guide for behaviour of every person within SA. Adolescents with disabilities feel that the purpose of the Constitution, such as healing previous social injustices, equality and freedom, being protected by the law and the emphasis on the improvement of the QoL for all South African citizens. The constant exclusion has made adolescents with disabilities feel that their rights to human dignity are being violated (Sarkin, 1999).

This chapter described the discussion of the findings of the study. The three themes were addressed that aimed to answer the two objectives of the study, namely:

- To explore the facilitators that impact on the occupational choices of high functioning late adolescents with CP in Gauteng.
- To explore the barriers that impact on the occupational choices of high functioning late adolescents with CP in Gauteng.

CHAPTER 6

6. CONCLUSION

6.1 INTRODUCTION

Within this chapter the researcher first presents an overview of the chapters within the study. Subsequently, the research approach and method used, as well as the research findings, are summarised to determine whether the formulated aims and objectives of this study were achieved. Thereafter, the researcher makes suggestions and recommendations with regard to the role and responsibilities of occupational therapists working with individuals with CP, and this is followed by a discussion of the limitations of the study. The researcher then applies the research findings to formulate recommendations and ends with a summary of this chapter.

6.2 SUMMARY OF THE CHAPTERS

6.2.1 Chapter 1: Conclusions Relating to the aims and Objectives of the study.

The aims of the study were to explore the facilitators and barriers that impact on the occupational choices of high functioning late adolescents with CP.

The objectives in this study were to:

- To explore the facilitators that impact on the occupational choices of high functioning late adolescents with CP in Gauteng.
- To explore the barriers that impact on the occupational choices of high functioning late adolescents with CP in Gauteng.

This study yielded important information surrounding the facilitators and barriers that impact on the occupational choices of high functioning late adolescents with CP in Gauteng, SA.

6.2.2 Chapter 2: Conclusions Relating to the Literature Review

The purpose of this chapter was to review the literature to assess the trends throughout the years, and assist the reader to understand different aspects, which emerged from previous studies, focusing on facilitators and barriers which impact on the occupational choices of high functioning late adolescents with CP.

Previous research and discussion have been conducted on the opinions of caregivers and family as well as personal experiences from the individual with CP including the

effects of living with CP. The research primarily focused on CP and its components, with an emphasis placed on studies within different countries and different cultures. More research is required to gain a better understanding of the lived experiences of individuals with CP, especially within the adolescent life stage, as they have been reported to have fallen through the cracks.

The value in researching CP within Gauteng, SA assists in providing accurate insights into CP and associated contextual facilitators and limitations in performing occupations. South Africa has been referred to as a diverse population, with different cultures, religions and races. South Africa has been referred to as being one of the most inequal countries in the world (Woolard, 2002). Context specific information is needed to initiate and develop integrated services whilst providing the best level of care available.

6.2.3 Chapter 3: Conclusions Pertaining to the Research Methodology

The research approach used in this study was qualitative in nature as the researcher was interested in understanding the processes and meanings gained through words and the responses of the participants.

For the purpose of this study, UNICEF's age band of late adolescence (15-19 years) was utilised, the target population was high functioning late adolescents with CP as the researcher required the participants to reflect at an abstract level, which provided rich data during data collection.

Purposive sampling using pre-selected criterion assisted with streamlining the research process. This assisted the researcher to remain relevant and explore the studies' primary research questions. Sample sizes were not fixed prior to the commencement of data collection; however, data saturation was reached after interviewing 12 research participants. All research participants attended a school for special needs and met the inclusion criteria. The information was consistent with the research question of the study.

The researcher requested that the school occupational therapists assist with participant recruitment, as the GMFCS, MACS and IQ testing is a routine assessment used for admission to the school for special needs. Briefing was conducted by the main researcher; however, dissemination and collection of the consent forms were done by the school occupational therapists.

The interviews were performed in the participants natural environment, where the principals readily gave permission for use of their venue. Informed consent readily provided informed consent, with no participants choosing to leave the study. The OPHI-II was utilised as the main data collection tool, which allowed gathering of pertinent information surrounding the participants perspectives of their ADLs, further exploring the perceived facilitators and barriers regarding the participants occupational choices (Kielhofner et al., 2001).

Data analysis was completed successfully using MAXQDA, transcripted immediately by an external person in the profession of research. Additionally, incorporating thematic analysis was performed for interpretation of the information gathered from the semi-structured interviews.

6.2.4 Chapter 4: Findings which Emerged from the Study

Chapter 4 provided a description of themes arising from the interviews. This research yielded three themes, namely:

- Inclusion in life's decisions and occupational choices
- Am I good enough? (feelings of inferiority)
- I am not safe.

6.2.4.3 Theme 1: Inclusion in life's decisions and occupational choices

Research participants highlighted that an important facilitator which impacts on their occupational choices is being included in life's decisions and occupational choices. Having familial and financial resources has been linked positively with spending quality time with family resulting in decreased isolation.

Familial resources and finances influence the affordability of technology, such as cell phones, iPads and PlayStation which has been found to have a positive impact on the occupational choices available.

The attendance of a school for learners with special needs has been a pertinent facilitator for all research participants. They expressed positive feelings of comfort and acceptance within the school for learners with special needs. Sport offered by the special school has offered a sense of accomplishment and has improved participants' self-esteem.

6.2.4.1 **Theme 2: am I good enough?**

Feelings of inferiority was the main theme, which supported objective 2, being highlighted as a barrier to the participants' occupational choices. Participants furthermore felt that they experienced decreased family support as well as exclusion from family events. Participants moreover expressed that they felt sub-human and are seen by their family as useless and unable to engage. In addition, research participants felt that their families blame them for their disability.

Community stigma with associated bullying have been reported by all research participants. They further revealed limitations pertaining to their participation due to preconceived judgement regarding their disability with associated staring and negative comments made about them. They experienced constant isolation by others and often felt that they are not understood by others, leading to feelings of inferiority.

Research participants commented on social isolation as a barrier to occupational choices. They often avoid social situations, and due to this lack of experience, they often struggle with appropriate social skills. Majority of the research participants expressed that they do not have any friends and spend most of their time alone.

Research participants further commented on their disability and related impairments as a barrier to their participation in occupations which they need and or want to perform. Many participants stated that their dependence on others and therefore a lack of independence is another barrier that they face.

6.2.4.2 **Theme 3: I am not safe**

Research participants highlighted their vulnerability, explaining that people within their environment and living situation is not safe. Their vulnerability was exasperated by their lack of mobility and ability to get themselves out of dangerous situations. Research participants expressed that they do not trust many people in their lives as they tend to get taken advantage of by others.

6.3 **CHAPTER 5: CONCLUSIONS PERTAINING TO THE DISCUSSION**

Chapter 5 discussed the findings from the study, which emerged during data analysis, with supporting verbatim quotes from research participants. The main findings from the study highlighted the themes: Am I good enough, am I safe and being included in life's decisions and occupational choices. These were discussed as emergent barriers and facilitators to the occupational choices of high functioning late adolescents with CP.

6.4 CHAPTER 6: CONCLUSION

This chapter provides the reader with a summary of the research report and conclusions pertaining to the aim and objectives of the study. Suggestions relating to the role and responsibilities of occupational therapists working with high functioning late adolescents with CP, especially to decrease the barriers, which emerged and enhance the facilitators, which emerged, will be proposed. The chapter concludes with a discussion of the limitations of the study and recommendations with reference to occupational therapy practice and future research relating to the topic of this study.

6.5 LIMITATIONS INHERENT IN THIS STUDY

Although the findings of the study contribute to our understanding of the facilitators and barriers that impact on the occupational choices of high functioning late adolescents with CP, this dissertation has several limitations which should be taken into consideration.

Methodological congruence refers to the different ways of thinking, leading to a different interpretation if the study is replicated or the methodology has changed. The challenge that needs to be met is if subsequent researchers use the same research procedure as the one used in the current study, albeit in different contexts. Each researcher, using different methods, will have different findings as the researcher is thinking in a different way. A researcher using a different methodological design and approach will most likely analyse the findings and discussion differently.

Interviews which evoked extensive in-depth knowledge were slightly longer than expected when compared to the pilot study, leading to needing extra movement breaks to ensure information is gathered. Fatigue due to the long interview process could inhibit future studies, and these studies would benefit by dividing the sessions throughout the day or week.

The analysis process occurred throughout the data collection process. The first two interviews had decreased informative questions, such as the ‘why’. Insights for these participants could have been missed due to the researcher’s decreased probing of participants’ answers.

Increasing the sample size, whilst expanding the locations of study within Gauteng, SA will assist in proving more holistic information surrounding the facilitators and barriers which impact on the occupational choices of high functioning late adolescents with CP.

Demographic information should be collected more in detail to establish specific location barriers and facilitators, such as common shopping malls where participants experience similar barriers and facilitators. Highlighting the difference in context, such as socioeconomic status and resources offered in different areas, may offer different barriers and facilitators to occupational choices and performance.

All participants were able to engage in an in-depth interview. Consequently, the experiences of adolescents with cerebral palsy who are not able to reflect on their experiences and verbally communicate their thoughts are not represented in this study.

This study did not aim to achieve generalization, but rather transferability. Making a generalisation based on the findings of the dissertation is not recommended due to the small sample size and areas which the researcher had access to. Future research should involve transferability, further data collection within different schools and locations with different functional levels of individuals with CP across Gauteng, SA. Future research could also provide a view of the barriers and facilitators, which emerge on a national level, collecting and analysing data across geographical areas within SA.

6.6 SUGGESTIONS OF THE FACTORS THAT INFLUENCE THE OCCUPATIONAL CHOICES OF HIGH FUNCTIONING LATE ADOLESCENTS WITH CEREBRAL PALSY IN GAUTENG

Feelings of inferiority has been a recurring barrier throughout the interviews. Barriers which emerged throughout the study should be addressed by their families, health care professionals and other pertinent people in their family. The adolescent with CP should build self-confidence throughout their lives so that they meet their developmental milestones appropriately.

Adolescents with CP should be made aware of their strengths and weaknesses, whilst using their strengths to assist with participating in their chosen occupational choices. By addressing this barrier to participation, emphasis should be placed on decreasing feelings of not being good enough and not feeling ‘normal’.

Early education of all members of the family surrounding general information about the diagnosis of CP and how to assist with facilitation of ADL’s and iADL’s will assist the individual with CP to build the confidence to participate in community events and make

friends. This will in turn decreases feelings of inadequacy and positively influences self-enhancement, therefore decreasing the increased risk for depression and isolation.

Feelings of inferiority hinders the fulfilment of life tasks such as intimacy, love, friendship, a sense of belonging and significance. Parents, health care professionals, teaching staff peers and community members, as the adolescents' support system should assist the individual to move through Havighurst's (1972) developmental milestones appropriately, so that the individual moves towards a purposeful life, showing courage and interest to successfully meet tasks and challenges (Havighurst, 1972; Manning, 2002).

Attitudes towards disabilities remains a pertinent barrier to the participation of high functioning late adolescents with CP. Families, communities and peers struggle to fully understand the challenges which an individual with a disability experience daily. This leads to exclusion, increasing the risk for isolation and depression. Accessibility and inclusive learning spaces, teacher training for inclusive education, exercising a multi-sectorial approach including decreasing barriers both within and outside the education system whilst fully involving the community to increase understanding surrounding disability and decrease stigma will contribute positively to overall participation.

Feelings of not being safe emerged as a pertinent barrier as it revealed feelings of fear and danger, especial within society. This limits their occupational participations and choices available. This further ostracises individuals with disabilities.

A power imbalance is noted within this target population due to their disability and limitations. The other party (such as peers and community members) often have an upper hand in the situation and generally hold the power in the relationship and associated communication. Society, especially parents, schools and health care professionals should be empowered to educate others within the environment to enhance understanding of the power imbalance which occurs.

An emphasis should be placed on constant education and guidance to appropriate responses to the individual with a disability. Individuals with disabilities should be taught their human and civil rights, with the responsibility from those around them to create safe and secure spaces.

The research participants of this study reported that feeling safe has been considered as one of the most important aspects of a person's life as it gives the individual a chance to enjoy their lives without fear of being harmed physically, psychologically, or financially. Educating individuals with disabilities that their voices will be taken seriously is needed to assist in adolescents with disabilities in feeling safe. In general, increased police visibility, increased lighting within the community as well as CCTV are strategies which can be employed to make the community safer for individuals with disabilities. Inclusion in life's decisions and occupational choices was the main facilitator which impacts on the occupational choices of high functioning late adolescents with CP, such as having a say in the choices of activities which are facilitated and performed.

Being included in life's decisions and occupational choices should be encouraged by health professionals whilst educating families, school staff as well as members of the society to enable and facilitate occupational choices and participation. Individuals with disabilities have the same rights as abled-bodied people, including the right to participate fully in their own lives' decisions and community life. Facilitation and development towards inclusion and self-identity whilst developing their own individual voice, which is heard and respected by others. This will impact on honouring human dignity, improve the individual's QoL positively, as well as advocate for their own disability, choices and needs.

6.7 RECOMMENDATIONS BASED ON THE RESEARCH FINDINGS

Based on the findings of the study the researcher formulated the following:
Occupational therapists and other health care professionals should further consult with adolescents with CP to address individual concerns and increase awareness of the needs and wants of individuals with CP, to assist with developing a holistic, individualised treatment programme.

Occupational therapists and other health care professionals can offer strategies for the promotion of facilitators by positively influencing and promoting occupational choices and participation in activities which the adolescent wants and need to perform.

Occupational therapists should consider the power of the collective due to the interconnectedness of the person within their social environment, as isolation is evident. Occupational therapists should empower families, individuals with disabilities, as well as society members to decrease barriers whilst engaging in the potential power of the collective. There is an utmost importance to work towards social change through

community development to further enable and encourage inclusiveness within the community.

Occupational therapists and other health care professionals may use this study to assist raising awareness within the community, as well as increasing the knowledge of disabilities within schools, communities, and family education at a level and language which is easily understood. A focus should be placed on education of the greater community surrounding decreasing their feelings of superiority and seeing individuals with disabilities as equals thus increasing participation within the community, as a collective. Increasing inclusion in life's decisions whilst empowering individuals with disabilities is recommended. Parents should be offered time and follow up appointments to fully support the parents and adolescents with CP.

Occupational therapists can further assist in overcoming barriers within therapy, which emerged from the study to ensure the adolescents with CP's occupational participation is positive, which will translate into repetition and therefore activities which they were previously struggling with or unable to perform will become more 'normal', increasing the adolescents with CP's occupational choices and participation, therefore increasing skills, self-esteem, and confidence.

It is evident from the study that high functioning late adolescents with CP feel inferior and therefore struggle to find their voice to speak up and communicate their needs and wants. An emphasis should be placed on the education of the individual with a disability, as well as their family to encourage and grow their confidence to educate others surrounding their disabilities as well as develop the voices of those who feel they have been forgotten and have been silenced. Individuals with disabilities should be empowered to take control of their own lives and advocate for their needs and wants.

6.8 RECOMMENDATION IN TERMS OF FUTURE RESEARCH

The researcher conducted semi-structured interviews with 12 high functioning late adolescents with CP to identify the facilitators and barriers that impact on the occupational choices and participation. This was based on semi-structured interviews with associated thematic analysis identified three recurring themes based on responses from research participants; inclusion in lifes' decisions and occupational choices, am I good enough and I am not safe. The researcher recommends the following in terms of future research pertaining to identifying and addressing barriers

and facilitators of high functioning late adolescents, which impacts on their occupational choices and participation.

Future research is recommended, especially in developing context and age-related local and global partnerships with other researchers, therapists and members of the community whilst sharing their research findings to increase the knowledge surrounding high functioning late adolescents with CP.

Further research is needed amongst the adolescents with disabilities, both nationally and internationally as it has been found that they often forgotten, being included in past studies as either an adult or excluded completely. This study concentrated on late adolescents with CP; further research is needed amongst this age category as well as expanding these ages so that barriers to meeting Havighurst's (1972) age-appropriate milestones throughout the years can better be identified (Havighurst, 1972; Manning, 2002). Society needs to work as a collective so that we can decrease these barriers to facilitate success in meeting these milestones appropriately, therefore providing the individual with an increased chance for success in life.

This study interviewed 12 research participants of different sexes. Increasing the number of research participants, as well as separating different sexes allows for deeper insights into the barriers and facilitators, which emerged during this study. Additional focuses and expansion into the themes, which emerged during the study, to either support, add or reject the findings of the study should be considered.

It is known that males, females and different cultures have different experiences in life, with different barriers and facilitators that they may experience. Separating this study's research question, whilst focusing on the different experiences of the different sexes will allow for deeper understanding of facilitators and barriers, especially due to the stereotyping of people with a disability, in life with East and Orchard's (2014) argument that 'individuals with disabilities are perceived by others as innocent, naive and asexual beings' (East & Orchard, 2014).

The research study could have been further replicated placing additional emphasis on adolescents with CP who present with communication difficulties so that their experiences and views are accurately represented, their voices are heard. The use of augmentative and alternative communication (AAC) can be used to facilitate gathering of pertinent information and experiences. However, it is important to include individuals

with disabilities opportunities to express their critical reasoning, about decisions that involve them.

Integration of multidisciplinary approaches should be encouraged, especially within universities throughout SA and globally. Involving different disciplines such as but not limited to Information Technology (IT) and engineering will should be encouraged, especially when addressing barriers and developing appropriate assistive devices to enhance participation of adolescents with disabilities.

Governmental support and funding are needed and should be distributed evenly throughout SA. Funding can be used to facilitate research surrounding disabilities, offering educational seminars and workshops to community members and improve resources and infrastructure of societies to encourage participation. Support is needed by society, parents and children with disabilities.

Dissemination of findings will occur in a variety of techniques and methods is needed to educate others on the facilitators and barriers. This will involve disseminating the current findings of the study through the department of education, publication in an accredited journal, presentations at pertinent events and trainings, such as at open days at schools and social events for families and individuals with disabilities. This also includes opportunities for community members to re-evaluate their preconceived ideas surrounding people with disabilities.

Pamphlets and information documents containing the main themes with associated suggestions to decrease barriers, whilst increasing the facilitators which emerged will be drawn up and offered to families, research participations, service and policy makers so that we can tackle the barriers in order to increase occupational performance.

6.9 SUMMARY

This research investigated the barriers that impact on the occupational choices of high functioning late adolescents with CP.

Theme 1, inclusion in life's decisions and occupational choices developed as the main theme to answer this research question. Aspects such as familial finances and the attendance of a school for learners with special needs associated with feelings of being "normal" whilst giving the adolescent with CP a feeling of belonging. The opportunity for adapted sport assists in increasing occupational choices and participation, whilst

giving the adolescent with CP a sense of accomplishment. Being included in life's decisions and occupational choices has been noted as a facilitator to achieving age-appropriate meeting of Havighurst's (1972) developmental stages, increasing the opportunity for success in meeting future milestones and success in life (Havighurst, 1972) .

Theme 2, 'I am not safe, emerged from the study which supported the barriers which high functioning late adolescent with CP experience. Feeling not safe and vulnerable within their immediate and social environment was supported by relevant literature and past studies. Not feeling safe, feelings of being scared and not trusting people within their environment emerged as barriers to their occupational choices and participation. This leads to self-isolation, lack of participation and impacts on the success of meeting age-appropriate development of Havighurst's (1972) developmental stages, therefore impacting on the success of future developmental stages (Havighurst,1972).

The third theme included feelings of inferiority with associated family and community stigma, lack of support and participation within their family occupations and social isolation impacting on participants' mental and physical health. Other categories discussed and correlated to literature were adolescents' dependence on others, identifying that their disability is one of the biggest barriers to their participation. This impacts on the ability of the individual with a disability in meeting their age-appropriate developmental milestones, as reported by Havighurst (1972), which impacts on the success of meeting future developmental stages (Havighurst, 1972; Manning, 2002).

This study found, in accordance with the South African Human Rights Commission (2018), disabled people continue to be marginalised and excluded from being able to fully participate within the society (Human Rights Commission, 2018). This study contributes to the body of knowledge surrounding high functioning late adolescents with CP.

This current study will be used to guide adolescents with CP, parents, families and healthcare practitioners to better prepare high functioning adolescents with CP to cope with life's changes and decrease barriers that they face whilst progressing through this difficult period in their life. The facilitators which emerged will be used to improve and assist the increase of meaningful activity participation, to ensure that their occupational performance and priorities are positive.

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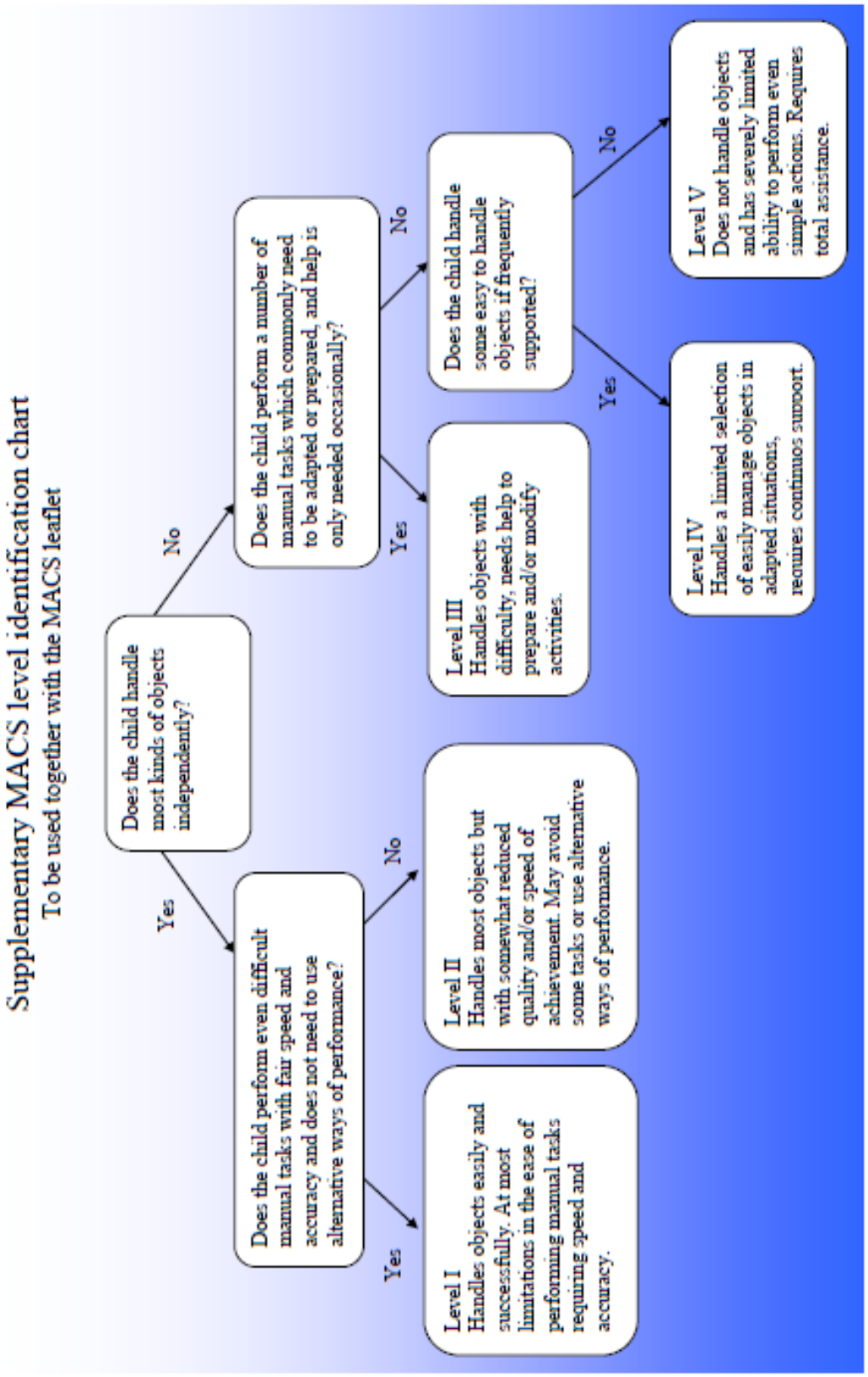
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APPENDIX 1

- **MANUAL ABILITY CLASSIFICATION SYSTEM FLOW CHART**



APPENDIX 2

- **MANUAL ABILITY CLASSIFICATION SYSTEM INFORMATION**

Manual Ability Classification System for Children with Cerebral Palsy 4-18 years

MACS classifies how children with cerebral palsy use their hands to handle objects in daily activities.

- MACS describes how children usually use their hands to handle objects in the home, school, and community settings (what they do), rather than what is known to be their best capacity.
- In order to obtain knowledge about how a child handles various everyday objects, it is necessary to ask someone who knows the child well, rather than through a specific test.
- The objects the child handles should be considered from an age-related perspective.
- MACS classify a child's overall ability to handle objects, not each hand separately.

Information for users

The Manual Ability Classification System (MACS) describes how children with cerebral palsy (CP) use their hands to handle objects in daily activities. MACS describes five levels. The levels are based on the children's self-initiated ability to handle objects and their need for assistance or adaptation to perform manual activities in everyday life. The MACS brochure also describes differences between adjacent levels to make it easier to determine which level best corresponds with the child's ability to handle objects.

The objects referred to are those that are relevant and age-appropriate for the children, used when they perform tasks such as eating, dressing, playing, drawing or writing. It is objects that are within the children's personal space that is referred to, as oppose to objects that are beyond their reach. Objects used in advanced activities that require special skills, such as playing an instrument are not included in this considerations.

When establishing a child's MACS level, choose the level that best describes the child's overall usual performance, in the home, school or community setting. The child's motivation and cognitive ability also affect the ability to handle objects and accordingly influence the MACS level. In order to obtain knowledge about how a child handles various everyday objects it is necessary to ask someone who knows the child well. MACS is intended to classify what the children usually do, not their best possible performance in a specific test situation.

MACS is a functional description that can be used in a way that is complement to the diagnosis of cerebral palsy and its subtypes. MACS assesses the children's overall ability to handle everyday objects, not the function of each hand separately. MACS does not take into account differences in function between the two hands; rather, it addresses how the children handle age-appropriate objects. MACS does not intend to explain the underlying reasons for impaired manual abilities.

MACS can be used for children aged 4–18 years, but certain concepts must be placed in relation to the child's age. Naturally there is a difference in which objects a four-year old should be able to handle, compared with a teenager. The same applies to independence –a young child needs more help and supervision than an older child.

MACS spans the entire spectrum of functional limitations found among children with cerebral palsy and covers all sub-diagnoses. Certain sub-diagnoses can be found at all MACS levels, such as bilateral CP, while others are found at fewer levels, such as unilateral CP. Level I includes children with minor limitations, while children with severe functional limitations will usually be found at levels IV and V. If typically developed children were to be classified according to MACS, however, a level "0" would be needed.

Moreover, each level includes children with relatively varied function. It is unlikely that MACS is sensitive to changes after an intervention; in all probability, MACS levels are stable over time.

The five levels in MACS form an ordinal scale, which means that the levels are 'ordered' but differences between levels are not necessarily equal, nor are children with cerebral palsy equally distributed across the five levels.

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Eliasson AC, Krumlinde Sundholm L, Rösblad B, Beckung E, Arner M, Ohrvall AM, Rosenbaum P. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability Developmental Medicine and Child Neurology 2006 48:549-554



What do you need to know to use MACS?

The child's ability to handle objects in important daily activities, for example during play and leisure, eating and dressing.

In which situation is the child independent and to what extent do they need support and adaptation?

I. **Handles objects easily and successfully.** At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

II. **Handles most objects but with somewhat reduced quality and/or speed of achievement.** Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

III. **Handles objects with difficulty; needs help to prepare and/or modify activities.** The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

IV. **Handles a limited selection of easily managed objects in adapted situations.** Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

V. **Does not handle objects and has severely limited ability to perform even simple actions.** Requires total assistance.

Distinctions between Levels I and II

Children in Level I may have limitations in handling very small, heavy or fragile objects which demand detailed fine motor control, or efficient coordination between hands. Limitations may also involve performance in new and unfamiliar situations. Children in Level II perform almost the same activities as children in Level I but the quality of performance is decreased, or the performance is slower. Functional differences between hands can limit effectiveness of performance. Children in Level II commonly try to simplify handling of objects, for example by using a surface for support instead of handling objects with both hands.

Distinctions between Levels II and III

Children in Level II handle most objects, although slowly or with reduced quality of performance. Children in Level III commonly need help to prepare the activity and/or require adjustments to be made to the environment since their ability to reach or handle objects is limited. They cannot perform certain activities and their degree of independence is related to the supportiveness of the environmental context.

Distinctions between Levels III and IV

Children in Level III can perform selected activities if the situation is prearranged and if they get supervision and plenty of time. Children in Level IV need continuous help during the activity and can at best participate meaningfully in only parts of an activity.

Distinctions between Levels IV and V

Children in Level IV perform part of an activity, however, they need help continuously. Children in Level V might at best participate with a simple movement in special situations, e.g. by pushing a button or occasionally hold undemanding objects.

APPENDIX 3

- **GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM**

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GMFCS – E & R
Gross Motor Function Classification System
Expanded and Revised

GMFCS - E & R © Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007
CanChild Centre for Childhood Disability Research, McMaster University

GMFCS © Robert Palisano, Peter Rosenbaum, Stephen Walter, Dianne Russell, Ellen Wood, Barbara Galuppi, 1997
CanChild Centre for Childhood Disability Research, McMaster University
(Reference: Dev Med Child Neurol 1997;39:214-223)

INTRODUCTION & USER INSTRUCTIONS

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. When defining a five-level classification system, our primary criterion has been that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The distinctions between Levels I and II are not as pronounced as the distinctions between the other levels, particularly for infants less than 2 years of age.

The expanded GMFCS (2007) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization's International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that **environmental** and **personal** factors may have on what children and youth are observed or reported to do. The focus of the GMFCS is on determining which level best represents the **child's or youth's present abilities and limitations in gross motor function**. Emphasis is on usual **performance** in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

The title for each level is the method of mobility that is most characteristic of performance after 6 years of age. The descriptions of functional abilities and limitations for each age band are broad and are not intended to describe all aspects of the function of individual children/youth. For example, an infant with hemiplegia who is unable to crawl on his or her hands and knees, but otherwise fits the description of Level I (i.e., can pull to stand and walk), would be classified in Level I. The scale is ordinal, with no intent that the distances between levels be considered equal or that children and youth with cerebral palsy are equally distributed across the five levels. A summary of the distinctions between each pair of levels is provided to assist in determining the level that most closely resembles a child's/youth's current gross motor function.

We recognize that the manifestations of gross motor function are dependent on age, especially during infancy and early childhood. For each level, separate descriptions are provided in several age bands. Children below age 2 should be considered at their corrected age if they were premature. The descriptions for the 6 to 12 year and 12 to18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

An effort has been made to emphasize abilities rather than limitations. Thus, as a general principle, the gross motor function of children and youth who are able to perform the functions described in any particular level will probably be classified at or above that level of function; in contrast, the gross motor function of children and youth who cannot perform the functions of a particular level should be classified below that level of function.

OPERATIONAL DEFINITIONS

Body support walker – A mobility device that supports the pelvis and trunk. The child/youth is physically positioned in the walker by another person.

Hand-held mobility device – Canes, crutches, and anterior and posterior walkers that do not support the trunk during walking.

Physical assistance – Another person manually assists the child/youth to move.

Powered mobility – The child/youth actively controls the joystick or electrical switch that enables independent mobility. The mobility base may be a wheelchair, scooter or other type of powered mobility device.

Self-propels manual wheelchair – The child/youth actively uses arms and hands or feet to propel the wheels and move.

Transported – A person manually pushes a mobility device (e.g., wheelchair, stroller, or pram) to move the child/youth from one place to another.

Walks – Unless otherwise specified indicates no physical assistance from another person or any use of a hand-held mobility device. An orthosis (i.e., brace or splint) may be worn.

Wheeled mobility – Refers to any type of device with wheels that enables movement (e.g., stroller, manual wheelchair, or powered wheelchair).

GENERAL HEADINGS FOR EACH LEVEL

LEVEL I	-	Walks without Limitations
LEVEL II	-	Walks with Limitations
LEVEL III	-	Walks Using a Hand-Held Mobility Device
LEVEL IV	-	Self-Mobility with Limitations; May Use Powered Mobility
LEVEL V	-	Transported in a Manual Wheelchair

DISTINCTIONS BETWEEN LEVELS

Distinctions Between Levels I and II - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

Distinctions Between Levels II and III - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

Distinctions Between Levels III and IV - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

Distinctions Between Levels IV and V - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.

© Palisano, Rosenbaum, Bartlett & Livingston, 2007

APPENDIX 4

- **OPHI-II INTERVIEW QUESTIONS WITH PROBES**

THE OCCUPATIONAL PERFORMANCE HISTORY INTERVIEW (VERSION 2.0) OPHI- II SEMI- STRUCTURED INTERVIEW QUESTIONS

OCCUPATIONAL ROLES

Student roles

- Tell me a little about yourself
- What does your studies/ going to school involve?
- What kind of responsibilities do you have/ things you have to do as a student?
    - How well do you handle these responsibilities/tasks?
    - Do you like doing them?
- What would you say is the main thing you get out of studying at school?
- What kind of student would you say you are?
    - Tell me something that you did recently as a daughter/son/partner that you are really proud of.
- Would you say that school is difficult for you?
- Do you think that your disability has affected your studies?

Friend/ volunteer, amateur, hobbyist and other roles

- In addition to your studies, is there anything else that takes up a lot of your time and energy, that is really important to you?
    - Or is there any special thing that you do a lot?

Religious/organization participation

- Do you actively participate in any organizations or in church/temple groups?
    - Tell me about it?
    - What kind of things do you do?
    - How did you get started?
- Why do you do this?
    - Is it just for fun or more serious?

DAILY ROUTINE

- Describe a typical day during the week.
    - Can you tell me about something that happened recently that typifies what this routine is really like for you?
- Is the weekend any different?
    - If yes- describe it.
- Are you satisfied with this routine?
    - If yes- what do you like about it?
    - If no- what do you dislike about it?
- If you were having a really good or really bad day, what would that day be like?
- What are the most important things in your routine?
    - Does your routine allow you to get done the things that are most important?

    - If no- what important things are you not able to do?
- Was your daily routine ever different?
    - Did you have any hobbies or projects that were part of your routine in the past?
    - Which was better for you?
- What is the most important thing to keep the same about your routine?
- What would you most like to change about your routine?
- Do you have any ongoing hobbies/projects that are part of your current routine?
    - Tell me about_____
    - How often do you do it?
    - How did you get started?
    - What do you like about it?
    - How long has this been a part of your routine?
- Do you have any hobbies or projects that were part of your routine in the past?

OCCUPATIONAL SETTINGS (ENVIRONMENT)

Home

- Give me a little tour of/ tell me about your home/room/apartment/dorm
    - Is your home/room/dorm comfortable?
    - Do you have enough privacy?
    - Cab you get around in your home/apartment/dorm?
    - Do you have the things there that you need in order to do what you want?
    - Are you ever bored there?
    - Do you like your surroundings?
        - Are they stimulating for you?
- What do you have to do to keep up your home/room/dorm?
    - Do you like doing this?
    - Are you able to do it okay?
- Who do you live with?
    - What kinds of things do you do together?
    - How do you get along?
- How would you describe things where you live? (for instance, which of the following describes your home/living situation: loving, fighting, stressful, calm, chaotic, busy, boring?)
- Is there anyone at home/ in your family who makes life stressful or difficult for you?
- If you need help with something, can you expect your family/ roommate etc. to give you a hand?
    - Can you give me an example?
- If you were feeling depressed or upset, could you expect your family/ roommate etc. to give you support?
    - Can you give me an example?

Major productive role

- Give me a little tour of/ tell me about your school? What is it like?
    - Is it well suited for you to get your studies/work done?
    - Do you have enough privacy?
    - Can you get around okay?
    - What are the main things you do at school?

        - Is it adequate for that?
        - Do you have the things there that you need to do what you want?
        - Are you bored there?
        - Are you ever stressed there?
        - Do you like your work surroundings?
- How would you describe things where you work? (for instance, which of the following describes your work situation: loving, fighting, stressful, calm, chaotic, busy, boring?)
- Who are the people you interact with most as a student?
- How do you get along with your teachers/ fellow students?
- Is there anyone at school who makes work difficult or stressful for you?
- If you need help with something can you expect you teachers or fellow students to give you a hand?
    - Can you give me an example?
- If you were feeling depressed or upset, could you expect your teachers or fellow students to give you advice or support?
    - Can you give me an example?

Leisure

- What are the main things you do to recreate and relax?
    - Where do you go for that?
    - Is it a good place to be?
    - Do you like the facilities/atmosphere?
    - Do they suit you well?
- Do you really have the places you want for relaxation or recreation?
- Who are they people you relax/ recreate with most?
    - How do you get along with them?
- Tell me about something you did recently that would show me what kind of atmosphere you are in when you relax or recreate.

ACTIVITY/ OCCUPATIONAL CHOICES

- How did you come to choose your line of studies?
- Do you get to do the things that you think are really important?
    - If yes- what are some of the things that are really important to you?
    - If no- can you tell me about those things that you don't get to do? And why?
- Have you been able to choose the things in your life that are important to you?
- Is there anything that routinely interferes with what you want to do?
- Do you feel you have enough time to do the things you enjoy?
    - If yes- do you have free time?
        - What are you likely to spend it doing?
        - What do you do for fun?
        - Can you tell me about the most recent time when you really had a lot of fun?
    - If no- why do you think you don't have the time?
        - Can you give an example of a time when you felt you did not have enough time to do the things you enjoy?
        - If can't answer-why don't you think you have fun anymore?

- Do you ever set goals for yourself/ plan for the future?
    - If yes- are you able to follow through?
        - If yes- can you give me an example of a time when you had a goal and you followed through with it?
        - If no- can you give me an example of a time when you had a goal and you were not able to follow through with it?
    - If no- so how do you make decisions to get things done?
- When you run into obstacles or difficulties, how do you handle it?
    - Can you give me an example?
- What do you think is the biggest challenge that you are facing now?

CRITICAL LIFE EVENTS

- What were the events or experiences that most shaped or changed your life?
    - Ask for each event
        - Tell me about_____
        - What happened?
        - What changes did it bring about?
- If you think about your life, what do you consider the time when you were doing best?
    - Tell me about this period
    - What made it so good?
- Tell me about something that happened at school where you felt especially successful?
- What do you consider the worst period in your life?
    - Tell me about this period?
    - What made it so bad?
- What do you consider your biggest failure in life/ tell me about something that happened at school where you felt especially unsuccessful?
- If you could make your future turn out as you wanted, what would you be doing?
    - What do you see yourself doing in the future? Is that how you'd like it to be

APPENDIX 5

- **PREDETERMINED OBSERVATION PROTOCOL**

THE FACTORS THAT INFLUENCE THE OCCUPATIONAL CHOICES OF HIGH FUNCTIONING LATE ADOLESCENTS (AGES 15-19) DIAGNOSED WITH CEREBRAL PALSY IN GAUTENG

Predetermined Observational Protocol

Date of interview	
Time of interview	
Interview number	
Location of interview	
School currently attending	

Question number	Time	Detailed description of behavioural reaction of participants	Reflective notes

APPENDIX 6

- **ETHICAL CLEARANCE FROM UNIVERSITY OF THE WITWATERSRAND**

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Post Graduate Affairs)

TO: Ms M Jagwanth
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

E-mail: miksha.jagwanth@gmail.com

CC: Supervisor: Dr F Adams <Fasloen.Adams@wits.ac.za>
and <HREC-Medical.ResearchOffice@wits.ac.za>

FROM: Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 19/12/2018

REF: *R14/49*

PROTOCOL NO: **M180969** *(This is your ethics application study reference number. Please quote this reference number in all correspondence relating to this study)*

PROJECT TITLE: *The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with cerebral palsy in Gauteng*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to the Government funding of the University.

MS/Works2000/iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Ms M Jagwanth

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M180969

NAME: (Principal Investigator)	Ms M Jagwanth
DEPARTMENT:	School of Therapeutic Sciences Department of Occupational Therapy Medical School University
PROJECT TITLE:	The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with cerebral palsy in Gauteng
DATE CONSIDERED:	28/09/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr F Adams
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	19/12/2018

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 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/We fully understand the conditions under which I am/we are authorised 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 to the Committee. I agree to submit a yearly progress report. When a funder requires annual re-certification, the application date will be one year after the date of the meeting when the study was initially reviewed. In this case, the study was initially reviewed in September and will therefore reports and re-certification will be due early 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 7

- **PARTICIPANT CONSENT FORM**

PARTICIPANT CONSENT SHEET

The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with Cerebral Palsy in Gauteng

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details:

Miss Miksha Jagwanth, Principal Investigator, telephone no. 084 443 5120, or by e-mail at miksha.jagwanth@gmail.com

Dr Fasloen Adams, Supervisor, on telephone no. 011 0717 3701, or by e-mail at Fasloen.Adams@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant : _____

Date : _____

Place : _____

Signature or mark : _____

Witnessed by:

Name of Witness : _____

Signature : _____

Date : _____

APPENDIX 8

- **PLAGIARISM DECLARATION SIGNED FORM**

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG | HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

DECLARATION:

Adherence to HREC (Medicafl Ethics Anolication Terms and Conditions

I, the undersigned, hereby declare that I have not collected data/ done secondary data analysis or any other form of research, prior to obtaining clearance certificate from the HREC (Medical) for study no:__**M171044**__

I have read and understood the terms and conditions on section 9 of HREC (Medical) anolication form. I confirm that it is my responsibility to ensure that I have received final HREC (Medical) Clearance before commencing any research.

Miksha Jagwanth

Name, Surname and Signature

Student/Staff no if applicable: 1846236

Date: 23/07/2018

Jaideen Adams

Name, Surname and Signature

Supervisor (if applicable)

Date: 23/07/2018

APPENDIX 9

- **PARTICIPANT ASSENT DOCUMENT**

Title: The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with Cerebral Palsy in Gauteng

Participant Assent Document

Interview number: _____

Hello, My name is Miksha Jagwanth, and I am an Occupational Therapist doing research on Cerebral Palsy. I am looking at the things that influence you and what you choose to do in your life. This will be anything and everything, including the things that help you or prevent you from being able to do something that you want to do.

I will be asking you some questions, and will be voice recording you, so I can remember what you said later on when I am putting all the answers, from all the other people together.

I will also ask you to fill out a form to tell me what you do in your everyday life and how important those things are to you.

You may become distressed and emotional while you are telling me about things in your past, and that is okay. If you do become upset at any time, let me know and we will stop the interview and I will send you to the school counsellor, so you can speak about what upset you, and you can work through it.

Are you willing to continue?

_____ _____

Participants Signature Date

_____ _____

Witness Signature Date

Contact details:

Miss Miksha Jagwanth, Principal Investigator, telephone no. 084 443 5120, or by e-mail at miksha.jagwanth@gmail.com

APPENDIX 10

- **GDE RESEARCH REQUEST FORM**



GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

For admin. use

GDE RESEARCH REQUEST FORM

REQUEST TO CONDUCT RESEARCH IN INSTITUTIONS AND/OR OFFICES OF THE GAUTENG DEPARTMENT OF EDUCATION

PARTICULARS OF THE RESEARCHER

1.1	**Details of the Researcher**
Surname and Initials:	JAGWANTH M
First Name/s:	MIKSHA
Title (Prof / Dr / Mr / Mrs / Ms):	MS
Student Number (if relevant):	1846236
ID Number:	9209260215080

1.2	**Private Contact Details**
Home Address	***Postal Address (if different)***
2 PATDENOROW PLACE	
UNIT 4 STANFORD GARDENS	SAME AS HOME ADDRESS
BEDFORDVIEW	
Postal Code: 2007	***Postal Code:***
Tel: 011 618 2300	
Cell: 0844435120	
Fax:	
E-mail:MIKSHA.JAGWANTH@GMAIL.COM	

PURPOSE & DETAILS OF THE PROPOSED RESEARCH

2.1	**Purpose of the Research (Place cross where appropriate)**
Undergraduate Study - Self	
Postgraduate Study - Self	X
Private Company/Agency – Commissioned by Provincial Government or Department	
Private Research by Independent Researcher	
Non-Governmental Organisation	
National Department of Education	
Commissions and Committees	
Independent Research Agencies	
Statutory Research Agencies	
Higher Education Institutions	

2.2	**Full title of Thesis / Dissertation / Research Project**
The factors that influence the occupational choices of high functioning late adolescents (ages 15- 19) diagnosed with Cerebral Palsy in Gauteng	

2.3	**Value of the Research to Education (Attach Research Proposal)**
The purpose of the study is to contribute to the body of knowledge surrounding how high functioning late adolescents spend their time, as well as the perceived facilitators and barriers that influence their occupational choices. It has been found that minimal research has been conducted in South Africa surrounding this topic, this research will attempt to fill the existing gaps in research. This information will be used to assist parents, family members and occupational therapists to understand their perceived needs and limitations so that we are able to address these barriers during treatment, as well as ensure that their occupational performance and priorities are positive.	

2.4	**Proposed date of completion of study / project and submission of research findings to GDE**
Completion date:	**30-06-2019**
Submission to GDE date:	**30-09-2019**

2.5	Student and Postgraduate Enrolment Particulars (if applicable)
Name of institution where enrolled:	UNIVERSITY OF WITWATERSTRAND
Degree / Qualification:	MSC OCCUPATIONAL THERAPY
Faculty and Discipline / Area of Study:	MSC OCCUPATIONAL THERAPY-NEUROLOGICAL CONDITIONS
Name of Supervisor / Promoter:	DR FASLOEN ADAMS

2.6	Employer (where applicable)
Name of Organisation:	DEPARTMENT OF EDUCATION
Position in Organisation:	OCCUPATIONAL THERAPIST
Head of Organisation:	MS FIKILE MTHEMBI
Street Address:	28 CRESSY STREET, KENSINGTON
	JOHANNESBURG
Postal Code:	2101
Telephone Number (Code + Ext):	011 618 2300
Fax Number:	011 624 2475
E-mail:	ADMIN@DOUGWHITEHEADSPECIAL.CO.ZA

2.7	PERSAL Number (where applicable)

6	3	5	3	2	4	8	3

PROPOSED RESEARCH METHOD/S

(Please indicate by placing a cross in the appropriate block whether the following modes would be adopted)

Questionnaire/s (If Yes, supply copies of each to be used)

YES	**X**	**NO**	

Interview/s (If Yes, provide copies of each schedule)

YES	**X**	**NO**	

Use of official documents

YES		**NO**	**X**
If Yes, please specify the document/s:			

Workshop/s / Group Discussions (If Yes, Supply details)

YES		**NO**	**X**

Standardised Tests (e.g. Psychometric Tests)

YES		**NO**	**X**
If Yes, please specify the test/s to be used and provide a copy/ies			

INSTITUTIONS TO BE INVOLVED IN THE RESEARCH

Type of Institutions (Please indicate by placing a cross alongside all types of institutions to be researched)

INSTITUTIONS	**Mark with X here**
Primary Schools	
Secondary Schools	
ABET Centres	
ECD Sites	
Governmental LSEN Schools	X
Further Education & Training Institutions	
Other	

Number of institution/s involved in the study (Kindly place a sum and the total in the spaces provided)

Type of Institution	**Total**
Primary Schools	
Secondary Schools	
ABET Centres	
ECD Sites	
Governmental LSEN Schools	**6**
Further Education & Training Institutions	
Other	
GRAND TOTAL	**6**

Name/s of institutions to be researched (Please complete on a separate sheet if space is found to be insufficient)

Name/s of Institution/s
PRETORIA SCHOOL FOR CEREBRAL PALSIED LEARNERS
FRANCES VORWERGSKOOL
FOREST TOWN SCHOOL
NUWE HOOPSKOOL
WESTRAND SCHOOL
MURIEL BRANDSKOOL

District/s where the study is to be conducted. ***(Please indicate by placing a cross alongside the relevant district/s)***

District	
Ekhuruleni North	
Ekhuruleni South	
Gauteng East	**X**
Gauteng North	
Gauteng West	**X**
Johannesburg Central	
Johannesburg East	**X**
Johannesburg North	
Johannesburg South	**X**
Johannesburg West	
Sedibeng East	
Sedibeng West	
Tshwane North	**X**
Tshwane South	**X**
Tshwane West	

If Head Office/s (Please indicate Directorate/s)

Number of learners to be involved per school (Please indicate the number by gender)

Grade	***1***		***2***		***3***		***4***		***5***		***6***	
Gender	**B**	**G**	**B**	**G**	**B**	**G**	**B**	**G**	**B**	**G**	**B**	**G**
Number												

Grade	***7***		***8***		***9***		***10***		***11***		***12***	
Gender	**B**	**G**	**B**	**G**	**B**	**G**	**B**	**G**	**B**	**G**	**B**	**G**
Number							**2**	**2**	**2**	**2**	**2**	**2**

Number of educators/officials involved in the study (Please indicate the number in the relevant column)

Type of staff	***Educators***	***HODs***	***Deputy Principals***	***Principal***	***Lecturers***	***Office Based Officials***
Number	**0**	**0**	**0**	**0**	**0**	**0**

Are the participants to be involved in groups or individually?

Participation	
Groups	
Individually	**x**

Average period of time each participant will be involved in the test or other research activities (Please indicate time in minutes)

Participant/s	**Activity**	**Time**
ALL	**INTERVIEW**	**90 MINS DIVIDED INTO 2 SESSIONS**
ALL	**QUESTIONAIRE**	**30 MINS**

Time of day that you propose to conduct your research.

Before school hours	**During Break**	**After School Hours**
X	**X**	**X**

School term/s during which the research would be undertaken

First Term	**Second Term**	**Third Term**
X		

CONDITIONS FOR CONDUCTING RESEARCH IN GDE

Permission may be granted to proceed with the above study subject to the conditions listed below being met and may be withdrawn should any of these conditions be flouted:
The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.
The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.
A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.
A letter / document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.
The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.
Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.
Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.
Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.
It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.
The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.
The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.
On completion of the study the researcher must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.
The researcher may be expected to provide short presentations on the purpose, findings, and recommendations of his/her research to both GDE officials and the schools concerned.
Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a summary of the purpose, findings, and recommendations of the research study.

DECLARATION BY THE RESEARCHER	
I declare that all statements made by myself in this application are true and accurate.	
I accept the conditions associated with the granting of approval to conduct research and undertake to abide by them.	
Signature:	
Date:	**08-11-2018**

NB. If a group of Students / Researchers will be conducting the same research in the same / different GDE Institutions, Annexure A (attached) must be completed and signed by each researcher.

DECLARATION BY SUPERVISOR / PROMOTER / LECTURER	
I declare that: (Name of Researcher)…MIKSHA JAGWANTH …….	
is enrolled at the institution / employed by the organisation to which the undersigned is attached.	
The questionnaires / structured interviews / tests meet the criteria of: ***Educational Accountability*** ***Proper Research Design*** ***Sensitivity towards Participants*** ***Correct Content and Terminology*** ***Acceptable Grammar*** ***Absence of Non-essential / Superfluous items***	
Surname:	**ADAMS**
First Name/s:	**FASLOEN**
Institution / Organisation:	**UNIVERSITY OF WITWATERSRAND**
Faculty / Department (where relevant):	**OCCUPATIONAL THERAPY**
Telephone:	**011 717 3701**
Fax:	**N/A**
E-mail:	**FASLOEN.ADAMS@WITS.AC.ZA**
Signature:	
Date:	**08-11-2018**

N.B. This form (and all other relevant documentation where available) may be completed and forwarded electronically to Diane.Buntting@gauteng.gov.za The last 2 pages of this document must however have the original signatures of both the researcher and his/her supervisor or promoter. (For Group Research Annexure A, must also have original signatures.) These pages may be faxed to (086 594 1781) or hand delivered (in a sealed envelope) to Diane Buntting, Room 509, 111 Commissioner Street, Johannesburg. All enquiries pertaining to the status of research requests can be directed to Diane Buntting on tel. no. 011 843 6503.

APPENDIX 11

- **DEMOGRAPHICAL INFORMATION FORM**

Title of the study:
The factors that influence the occupational choices of high functioning late adolescents (ages 15- 19) diagnosed with Cerebral Palsy in Gauteng.

Biographical information sheet

Date:	
Interview number:	
School:	
Diagnosis:	
Date of birth/ age:	
Grade:	
Gender:	
Medication :	
General area/location:	
Home language:	
Assistive devices needed:	

APPENDIX 12

- **LETTER TO PRINCIPALS OF SCHOOLS**

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

Miksha Jagwanth
2 Patdenorow Place
Bedfordview
Unit 4
2007

The Principal
School's name here
Address of school

17 August 2018

Dear Sir, Madam

My name is Miksha Jagwanth and I am an occupational therapist currently working at Doug Whitehead School. I am completing my master's degree in occupational therapy at the University of Witwatersrand. In order to complete my degree, I am required to do a research report. The title of the study is: "The factors that influence the occupational choices of high functioning late adolescents (ages 15- 19) diagnosed with Cerebral Palsy in Gauteng ".

The aim of this research project is to explore how high functioning late adolescents with cerebral Palsy spend their time, as well as explore their perceptions of the facilitators and barriers that influence their choices. The significance of the study is that it will aid in the body of knowledge surrounding high functioning late adolescence Cerebral Palsy. The study hopes to help guide parents, families and healthcare practitioners to prepare high functioning Cerebral Palsy adolescents to cope with these changes and decrease the barriers that they face whilst progressing through this difficult period in their life.

This letter serves as a request to perform my research at your school, *(name of school)* and to make use of an area that is private, to which I can conduct the interviews.

The researcher will conduct a semi-structured interview, roughly around an hour to an hour and a half, this will be done before school or during break times. A questionnaire will be conducted afterwards, which will take roughly 30 minutes to complete. The questionnaire will provide us with information surrounding which activities are important to the individual. The interview and questionnaire will not interfere with any participants academical work. The results will be available to you following the completion of the study, as well as to the participants on request.

The parents or guardian will be informed about the study and asked to give written consent for their child to participate in the study. On the day of the assessment the learner will also be asked to give verbal and written assent that they are willing to participate in the study. There will also be a witness present to confirm that the learner has given assent.

Participation is voluntary, this means that the parents and learner may refuse to participate with no penalty or loss of benefits which they are entitle to. They may also decide to discontinue participation at any time without penalty loss of benefits to which they are entitled to both within the classroom as well as during school therapy.

There are no known risks involved with being involved in the study, other than possibly becoming distressed and emotional due to the recalling of past experiences (for example: reflecting on possible bullying by other students) If this should happen, the interview will be stopped immediately, and the research participant will be sent to the school counsellor for further assistance.

All the participants personal information such as name, date of birth and results of the assessment will be kept confidential and only known to the researcher and supervisor. To ensure confidentiality data will be coded with no names attached and this data will be kept in a secure location by the researcher.

If you have any questions you are welcome to contact me, Miksha Jagwanth at Doug Whitehead School on 011 618 2300 during school hours or on 084 443 5120.

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 concerns or complaints, you can contact the chair and secretariats of the Wits Human Research Ethics Committee (Medical): **Chairperson**: peter.cleaton-jones1@wits.ac.za or **Administrators**: Ms Zanele Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng Tel 011 717 2700/2656/1234/1252 or Email: HREC-Medical.ResearchOffice@wits.ac.za

Your permission to allow me to conduct my research at your school will be greatly appreciated.

Yours Sincerely,

Miksha Jagwanth
B. Occupational Therapy (UKZN)

APPENDIX 13

- **CHANGES REQUIRED FOR PROPOSAL**

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PROTOCOL ASSESSORS MEETING

Candidate Full Name: Milesha Jagwanth

Student Number: 1846236 Date: 15 August 2018

School / Department / Division: OT

1. **Type of study** *(tick all that apply)*:

- o Quantitative
- o Qualitative
- o Mixed Methods
- o Laboratory
- o Clinical
- o Other, please specify.....

2. **Is title of the study appropriate** (*preferably fewer than 20 words*)? Yes ☑ No ☐

Comments:

3. **Are the study objectives clear and linked to the research aim and title?** Yes ☐ No ☐

Comments: Revise Aim & objective => terminology "explore vs determine"
Please add in brief background on why we are including high functioning individuals / highlighting this group.

4. **Is the design of the study appropriate to meet the study objectives?** Yes ☑ No ☐

Comments:

03/03/2016

1

5. **Are the proposed methods and tools appropriate to meet the research objectives?** Yes / No

Comments: More detail on thematic analysis (esp. qualitative analysis) => concepts -> categories
Procedure on ethics can be reduced
Detail about how we can merge the data
Clarify order of tests ; Add in information regarding drugs individuals may be on => Data collection sheets

6. **Is the study feasible within the resources of:**

a) The applicant? Yes / No

b) The department? Yes / No

c) The time frame? Yes / No

7. **If this is a PhD protocol assessment:**

a) Is the content original? Yes / No

b) Does the content show the scope and depth of a PhD? Yes / No

Comments:

Do you recommend:

i. Additional revision/amendment of the protocol? Please be specific on the recommendations being made:
Consider the pharmacological management affecting questionnaire answers

ii. The appointment of a Co-Supervisor? Yes / No

Nominee/s:

03/03/2016

Overall recommendation regarding the protocol:

i. Revision of the protocol to the satisfaction of the Supervisor (**NB: if HoD approval is also required, please specify**): [Yes ✓] [No]
*(**Candidate**: one copy, list of corrections with page numbers and Supervisor approval letter – submit to PG Office).*

ii. Revision of the protocol to the satisfaction of the Assessor Group/Chair: [Yes] [No]
*(**Candidate**: one copy, list of corrections with page numbers, Supervisor approval letter – submit to PG Office and PG Office to forward to the Assessor Group Chair).*

iii. Revision of the protocol and resubmission of the revised protocol to the next Assessor Group Meeting: [Yes] [No]
*(**Candidate**: six copies, list of corrections with page numbers, Supervisor approval letter – submit one copy to PG Office / 5 to school assessor group administrator / for PhD, all six copies to be submitted to the PG Office).*

iv. Candidate goes ahead (*no revision required*): [Yes] [No]

Details of Assessors:

Name:	Email:	Sign:
Natala Naphylar	natala.naphylar@wits.ac.za	
Nkumbulwe Kiggs	[illegible]	
R van Zyl	Robyn.vanZyl@wits.ac.za	
Aimée Stewart	aimee.stewart@wits.ac.za	AStewart

Details of Assessor Group Chair:

Name:	Email:	Sign:
R van Zyl	Robyn.vanZyl@wits.ac.za	

Date: 15 August 2018

APPENDIX 14

- **STATEMENT FOR SUPERVISION**

Faculty of Health Sciences, Postgraduate Office
Phillip Tobias V 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

STATEMENT OF PRINCIPLES FOR POSTGRADUATE SUPERVISION

IN A CONTEXT OF ACADEMIC FREEDOM AND WITHIN A FRAMEWORK OF INDIVIDUAL AUTONOMY AND THE PURSUIT OF KNOWLEDGE THIS STATEMENT IS WRITTEN IN THE BELIEF THAT THERE IS A RECIPROCAL RELATIONSHIP AND MUTUAL ACCOUNTABILITY BETWEEN SUPERVISOR AND STUDENT.

THE SUPERVISOR AND THE STUDENT:

1. Will establish agreed roles and clear processes to be maintained by both parties. In the case of join supervision everybody's role needs to be clarified.
2. Will meet regularly and as frequent as is reasonable to ensure steady progress towards the completion of the proposal, research report, or dissertation or thesis. This time varies but the normal minimum requirement for face-to-face contact spread across each year of registration is: 10 contact hours for an Honours project, 15 contact hours for a Masters by a research report and 24 contact hours for a Masters by dissertation and a PhD.
3. Will keep appointments, be punctual and respond timeously to messages.
4. Will keep one another informed of any planned vacations or absences as well as changes in his/her personal circumstances that might impact on the work schedule. Unplanned absences or delays should be discussed as soon as possible and arrangements should be made, to catch up lost time.
5. Will ensure that research on animal or human subjects is concluded according to the procedures and the requirements of the relevant University Ethics committee.
6. Will together complete progress reports on the research project, as requested by each Faculty Graduate Studies Committee.

THE SUPERVISOR

1. Undertakes to provide guidance for the student's research project in relation to the design and scope of the project, the relevant literature and information sources, research methods of data analysis.
2. Has a responsibility to be accessible to the students.
3. Will be prepared for the meeting with the student. This includes being up-to-date on the latest work in his/her area of expertise.
4. Will expect written work as jointly agreed, and will return that work with constructive criticism within a timeframe (a suggestion of 2-4 weeks) jointly agreed at the outset of the research.
5. Will provide advice that can help the student to improve his/her writing. This may include referrals for language training and academic writing. The supervisor will provide guidance on technical aspects of writing such as referencing as well as on the discipline specific requirements. Detailed correction of drafts and instruction in aspects of language and style are not the responsibility of the supervisor.
6. Will support the student in the production of a research report, dissertation or thesis. Provision should be allowed for adequate, mutually respectful, discussion around recommendations made.

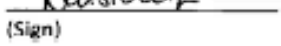
Student Signature: 

Supervisor 1 Signature: 

Supervisor 2 Signature: _____

Supervisor 3 Signature: _____

RECOMMENDATION BY HEAD OF DIVISION / DEPARTMENT / SCHOOL:

Daleen Cashleijn		23/02/2015
(Full name(s) and Surname)	(Sign)	(Date)

APPROVAL BY CHAIR OF ASSESSOR GROUP:
(On behalf of the FGSC)

(Full name(s) and Surname)	(Sign)	(Date)

PLEASE NOTE: RECOMMENDATION FOR APPOINTMENT OF SUPERVISOR(S) FOR CIRCULATION TO THE FGSC FOR APPROVAL

APPENDIX 15

- **APPOINTMENT OF SUPERVISOR**

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG | FACULTY OF HEALTH SCIENCES

RECOMMENDATION FOR APPOINTMENT OF SUPERVISOR(S) OF RESEARCH REPORT, DISSERTATION OR THESIS

Motivation / Reason for Appointment: The supervisor is experienced in the methodology and the topics falls within her research niche area.

Recommendation of Division / Department / School:
Recommended

Student Surname and Full name(s)	Miksha Jagwanth
Student number	1846236
Degree	MSc in Occupational Therapy
Div / Dept / School	
Title	The facilitators and barriers influencing the occupational choices of high functioning late adolescents with Cerebral Palsy.

(Supervisor 1): _Dr Fasloen Adams
(Name &Surname)
Supervision %: 100%

Supervisor Qualifications: PhD

Supervisor Department: Occupational Therapy

Supervisor Telephone: 73701 E-mail: Fasloen.adams@wits.ac.za

Supervisor 2: _____
(Name &Surname)
Supervision %: _____

Supervisor Qualifications: _____

Supervisor Department: _____

Supervisor Telephone: _____ E-mail: _____

Student Signature: _____

Supervisor 3: _____
(Name &Surname)
Supervision %: _____

Supervisor Qualifications: _____

Supervisor Department: _____

Supervisor Telephone: _____ E-mail: _____

1

APPENDIX 16

- **PARTICIPANT AUDIO CONSENT FORM**

CONSENT FORM FOR AUDIO RECORDING OF STUDY PARTICIPATION

The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with Cerebral Palsy in Gauteng

I hereby consent to audio recording of the interview
.
I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Contact details:

Miss Miksha Jagwanth, Principal Investigator, telephone no. 084 443 5120, or by e-mail at miksha.jagwanth@gmail.com

Dr Fasloen Adams, Supervisor, on telephone no. 011 0717 3701, or by e-mail at Fasloen.Adams@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant: _____
Date: _____
Place: _____
Signature or mark _____

Appendix: 17

Witnessed by:

Name of Witness: _____
Signature: _____
Date: _____

APPENDIX 17

- **SIGNED PERMISSION FROM PRINCIPALS**

WITS UNIVERSITY

SCHOOL PRINCIPAL CONSENT SHEET

The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with Cerebral Palsy in Gauteng

I give consent for Miksha Jagwanth, a student at Witwatersrand University, to approach learners, ages 15-19 diagnosed with Cerebral Palsy to participate in the above mentioned study.

I have read the project information statement explaining the purpose of the research project and understand that:

1. The role of the school is voluntary
2. I may decide to withdraw the schools participation at any time without penalty
3. Learners ages 15-19, diagnosed with Cerebral Palsy, will be invited to participate and that permission will be sought from them and also their parents.
4. Only learners who consent and whose parents consent will participate in the study.
5. All information obtained will be treated in the strictest confidence.
6. The learner's names will not be used and individual learners will not be identified in any written reports about the study.
7. Participants may withdraw from the study at any time without penalty.
8. Audio recordings will be used for data gathering purposes.
9. A report of the findings will be made available to the school.
10. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Contact details:

Miss Miksha Jagwanth, Principal Investigator, telephone no. 084 443 5120, or by e-mail at miksha.jagwanth@gmail.com

Dr Fasloen Adams, Supervisor, on telephone no. 011 0717 3701, or by e-mail at Fasloen.Adams@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of school: New Hope School

Mr C. Venter

Principal

15/11/'18

Date

Signature

NUWE HOOP SKOOL
~~NEW HOPE SCHOOL~~
Privaatsak 36085 Private Bag
MENLO PARK 0102
Tel: 012 460 2234/5
Tel: 012 346 2127/8
Faks: 012 346 2750

WITS
UNIVERSITY

SCHOOL PRINCIPAL CONSENT SHEET

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Dr Fasloen Adams, Supervisor, on telephone no. 011 0717 3701, or by e-mail at Fasloen.Adams@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of school: Muriel Brand School

J. d. de Jager

Principal

2018/11/13

Date

Signature

MURIEL BRAND SKOOL
MURIEL BRAND SCHOOL
PRIVAATSAK/PRIVATE BAG X30
1540 BRAKPAN

WITS
UNIVERSITY

SCHOOL PRINCIPAL CONSENT SHEET

The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with Cerebral Palsy in Gauteng

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Dr Fasloen Adams, Supervisor, on telephone no. 011 0717 3701, or by e-mail at Fasloen.Adams@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of school: FRANCES VORWERG SCHOOL

QINISO MTHIMKHULU

Principal

29-11-2018

Date

Signature

Frances Vorweg
Skool / School
School Stamp
29-11-2018
THE PRINCIPAL
Tel: 683-3390
Posbus/P.O. Box 82239, Southdale, 2135
GAUTENG EDUCATION DEPARTMENT

WITS UNIVERSITY

SCHOOL PRINCIPAL CONSENT SHEET

The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with Cerebral Palsy in Gauteng

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I have read the project information statement explaining the purpose of the research project and understand that:

1. The role of the school is voluntary
2. I may decide to withdraw the schools participation at any time without penalty
3. Learners ages 15-19, diagnosed with Cerebral Palsy, will be invited to participate and that permission will be sought from them and also their parents.
4. Only learners who consent and whose parents consent will participate in the study.
5. All information obtained will be treated in the strictest confidence.
6. The learner's names will not be used and individual learners will not be identified in any written reports about the study.
7. Participants may withdraw from the study at any time without penalty.
8. Audio recordings will be used for data gathering purposes.
9. A report of the findings will be made available to the school.
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Miss Miksha Jagwanth, Principal Investigator, telephone no. 084 443 5120, or by e-mail at miksha.jagwanth@gmail.com

Dr Fasloen Adams, Supervisor, on telephone no. 011 0717 3701, or by e-mail at Fasloen.Adams@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of school: WEST RAND SCHOOL

M.J. COETZER

Principal

2018-11-21

Date

Signature

WESRANDSE SKOOL
PRIVAATSAK/PRIVATE BAG X2026
2018-11-21
KRUGERSDORP 1740
WEST RAND SCHOOL

APPENDIX 18

- **DOE SIGNED PERMISSION**

Appendix: 18

GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

8/4/4/1/2

GDE RESEARCH APPROVAL LETTER

Date:	19 November 2018
Validity of Research Approval:	04 February 2019 – 30 September 2019 2018/347
Name of Researcher:	Jagwanth M
Address of Researcher:	2 Patdenorow Place
	Unit 4 Stanford Gardens
	Bedfordview, 2007
Telephone Number:	011 618 2300 084 443 5120
Email address:	MIKSHA.JAGWANTH@GMAIL.COM
Research Topic:	The factors that influence the occupational choices of high functioning late adolescents (ages 15- 19) diagnosed with Cerebral Palsy in Gauteng
Type of qualification	MSC OCCUPATIONAL THERAPY
Number and type of schools:	SIX LSEN Schools.
Districts/HO	Gauteng East, Gauteng West, Johannesburg East, Johannesburg South, Tshwane North and Tshwane South.

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

19/11/2018

The following conditions apply to GDE research. The researcher may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

1

Making education a societal priority

Office of the Director: Education Research and Knowledge Management
7th Floor, 17 Simmonds Street, Johannesburg, 2001
Tel: (011) 355 0488
Email: Faith.Tshabalala@gauteng.gov.za
Website: www.education.gpg.gov.za

1. *The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*
2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*
4. *A letter / document that outline the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher/s must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

.....

Mr Gumani Enos Mukatuni
Acting CES: Education Research and Knowledge Management

DATE: 19/11/2018

Office of the Director: Education Research and Knowledge Management
7th Floor, 17 Simmonds Street, Johannesburg, 2001
Tel: (011) 355 0488
Email: Faith.Tshabalala@gauteng.gov.za
Website: www.education.gpg.gov.za

APPENDIX 19

- **DECLARATION OF ADHERENCE TO THE HREC TERMS AND CONDITIONS**

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

DECLARATION:

Adherence to HREC (Medical) Ethics Application Terms and Conditions

I, the undersigned, hereby declare that I have not collected data/ done secondary data analysis or any other form of research, prior to obtaining clearance certificate from the HREC (Medical) for study no: **M171044**

I have read and understood the terms and conditions on section 9 of HREC (Medical) application form. I confirm that it is my responsibility to ensure that I have received final HREC (Medical) Clearance before commencing any research.

Miksha Jagwanth

Name, Surname and Signature

Student/Staff no if applicable: 1846236

Date: 23/07/2018

Jaden Adams

Name, Surname and Signature

Supervisor (if applicable)

Date: 23/07/2018

APPENDIX 20

- **PARENTAL CONSENT FORM**



PARENT/CAREGIVER CONSENT SHEET

The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with Cerebral Palsy in Gauteng

I, _____ Parent/Guardian of _____

A learner at _____School, having received a Participation Information sheet, agree and

understand:

1. Why the study is being conducted and what the intended outcomes will be
2. That participation of my child/ward is purely voluntary
3. That my child/ward may withdraw at any time with any reasons and without any adverse consequences to him/her
4. Even if I initially consent to allow participation in the study, you or your child/ward may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected from your child for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
5. that there will be no immediate benefit to me or my child/ward, should I agree to allow participation, nor will I receive any payment; conversely, participation will not cost me or my child/ward anything but my child's time;
6. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Contact details:

Miss Miksha Jagwanth, Principal Investigator, telephone no. 084 443 5120, or by e-mail at miksha.jagwanth@gmail.com

Dr Fasloen Adams, Supervisor, on telephone no. 011 0717 3701, or by e-mail at Fasloen.Adams@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Date: _____

Place: _____

Signature _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

APPENDIX 21

- **PARENTAL INFORMATION DOCUMENT**

STUDY TITLE: THE FACTORS THAT INFLUENCE THE OCCUPATIONAL CHOICES OF HIGH FUNCTIONING LATE ADOLESCENTS (AGES 15- 19) DIAGNOSED WITH CEREBRAL PALSY IN GAUTENG.

PARENT INFORMATION DOCUMENT

Dear Parent

Introduction:
My name is Miksha Jagwanth, an occupational therapist currently pursuing my masters at the University of Witwatersrand. I am doing my research on the occupational choices of high functioning adolescents aged 15-19, that are diagnosed with Cerebral Palsy.

Research is just the process to learn the answer to a question. In this study, we want to learn how adolescents (teenagers) with Cerebral Palsy spend their time, as well as what helps them (facilitators) and what prevents them (barriers) from being able to make choices regarding what they do with their time.

With the information I hope to gather from this research, I aim to help parents, families and other occupational therapists help adolescents to cope with changes of growing up, as well as decrease barriers that they face whilst moving through the difficult period of adolescence.

Invitation:
Your child has been invited to take part in this research project. Before you agree, it is important for you to fully understand what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Please feel free to contact me if you have any questions, or you would like more information.

What is involved in the study
The study is qualitative, which means that we want to understand your child's life experiences and beliefs in detail, using an interview which should take around 2 hours of your child's your time. Along with the interview, we have a short questionnaire about how easy it is for your child to partake in certain activities, as well as how important they are to them. For example: is it easy for your child to get along with others, does your child think getting along with others is important?

The researcher will come to your child's school, so there will be no financial implications involved to you in this study.

The researcher aims to interview around 8 other participants, who are also 15- 19 years old, with Cerebral Palsy and that live in Gauteng.

Risks:
There are no known risks involved with being involved in the study, other than your child possibly becoming distressed and emotional due to the recalling of past experiences (for example: reflecting on possible bullying by other students) If this should happen, the interview will be stopped immediately, and your child will be sent to the school counsellor for further assistance.

Benefits of being in the study.
Whilst there are no immediate benefits for those participating in the research, it is hoped that this work will be beneficial to other learners with Cerebral Palsy once the study is completed.

The participant will be given pertinent information on the study while involved in the project and after the results are available.

Participation is voluntary: if you or your child chose to not participate or your child wishes to discontinue their participation, there will be no penalty or loss of benefits to which the participant is otherwise entitled.

Confidentiality: Efforts will be made to keep personal information confidential.
Confidentiality and privacy will be maintained at all times during the entire research process. This will be ensured through the usage of a private area whilst conducting the interviews. After the interview has been conducted, the transcribed sheet will remain anonymous and the researcher will be sure to not disclose any personal information regarding the participants during the analysis and interpretation phase. Your child's name will be substituted with pseudonyms

All data collection tools and recordings will be transferred to a password protected device, where only the researcher and supervisor will have access to. Electronic data will be backed up regularly and will be disposed of after six years, where tools for permanent deletion and shredding will be utilized

Contact details of researcher:
For further information, please feel free to contact:

Miss Miksha Jagwanth, Principal Investigator, telephone no. 084 443 5120, or by e-mail at miksha.jagwanth@gmail.com

Dr. Fasloen Adams, Supervisor, on telephone no. 011 0717 3701, or by e-mail at Fasloen.Adams@wits.ac.za

Contact details of HREC administrator and chair
Please use the details below to report any complaints/ problems
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

APPENDIX 22

- **ACCEPTANCE OF TITLE OF THE STUDY**

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

30 October 2018
Person No: 1846236
PAG

Ms M Jagwanth
2 Patedorow Road, Unit 4 Stanford Gardens
Bedfordview
Johannesburg
2007
South Africa

Dear Ms Miksha Jagwanth

Master of Science in Occupational Therapy: Approval of Title

We have pleasure in advising that your proposal entitled has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX 23

- **REQUEST PERMISSION FORM FROM PRINCIPALS**

WITS UNIVERSITY

SCHOOL PRINCIPAL CONSENT SHEET

The factors that influence the occupational choices of high functioning late adolescents (ages 15-19) diagnosed with Cerebral Palsy in Gauteng

I give consent for Miksha Jagwanth, a student at Witwatersrand University, to approach learners, ages 15-19 diagnosed with Cerebral Palsy to participate in the above mentioned study.

I have read the project information statement explaining the purpose of the research project and understand that:

1. The role of the school is voluntary
2. I may decide to withdraw the schools participation at any time without penalty
3. Learners ages 15-19, diagnosed with Cerebral Palsy, will be invited to participate and that permission will be sought from them and also their parents.
4. Only learners who consent and whose parents consent will participate in the study.
5. All information obtained will be treated in the strictest confidence.
6. The learner's names will not be used and individual learners will not be identified in any written reports about the study.
7. Participants may withdraw from the study at any time without penalty.
8. Audio recordings will be used for data gathering purposes.
9. A report of the findings will be made available to the school.
10. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Contact details:

Miss Miksha Jagwanth, Principal Investigator, telephone no. 084 443 5120, or by e-mail at miksha.jagwanth@gmail.com

Dr Fasloen Adams. Supervisor, on telephone no. 011 0717 3701, or by e-mail at Fasloen.Adams@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of school: _____

_____ _____

Principal *Signature*

_____

Date

School Stamp

APPENDIX 24

- **LETTER OF CHANGES REQUIRED FROM HREC**

Name: Miksha Jagwanth Student number: 1846236

School/ department: Occupational therapy

Assessor meeting: 15th August 2018

Letter of corrections:

Changes suggested	Paragraph/ line number	Changes made
Revise aim and objection" explore Vs determine"	Section 1.5 Aim of the study Section 1.5.1- line 2	The aim of the study is to explore and describe how high functioning late adolescents (ages 15-19) diagnosed with CP currently spend their time, as well as explore their perceptions of the facilitators and barriers that influence their occupational choices. To determine how high functioning late adolescents between the ages of 15-19, diagnosed with CP spend their time
Add in brief background on why we are including high functioning individuals/targeting this group	Section 2.2 participants; sub-section population, line 4	High functioning learners with CP will be focused on as the researcher requires participants to be able to reflect at an abstract level, which will provide rich data during data collection.
More detail on thematic analysis	Section 3.5 analysis of data, line 6-15	Once data has been collected, the interviews will be transcribed, and field notes typed in order to sort and arrange the data. The next step will be to read the data collected so the researcher is able to gain a sense of overall meaning and reflect on the information that is collected. Coding of the data will follow which will be based on the emerging information collected. The information from the semi-structured interview and the questionnaire will be triangulated and analysed accordingly. The coding process will include a description of the setting where the research participants are based, as well as the major themes which came across during the reading of the data. These themes will be further explored, interrelated and a narrative passage will be used to covey the findings of the analysis. The findings of the study will then be interpreted accordingly(Creswell, 2003)
Procedure on ethics reduced	Section 3.6 Ethical clearance Sub- section 1 through 4	*Minimising risk of harm* The research will minimise the risk of harm by upholding the principles of beneficence, aiming to do good, through adding to the body of knowledge surrounding disability. The possibilities of distress will be communicated to the participants prior to data

		collection, however should they become distressed due to recalling of past experiences, the interview will be stopped, and they will be sent to the school counsellor immediately, thus ensuring non-maleficence. *Obtaining informed consent* The research participants and their parents/legal caretakers will be informed about the aims, benefits, risks and the requirements of the participant in a language and using terms that they can understand through a written participant information sheet, thus an informed consent can be given by both parties (P. Roberts & Priest, 2010). This will be sent home by the occupational therapists *Please see appendix 6 for information sheet and appendix 7 for consent form.* *Protecting anonymity and confidentiality* Confidentiality and privacy will be maintained at all times during the entire research process. This will be ensured through the usage of a private area whilst conducting the interviews as well as the omission of names and personal information during transcription. Information will be stored on a password protected device(P. Roberts & Priest, 2010). *Avoiding deceptive practices and competence* This research study will not be deceptive in any way; all information will be disclosed to the parents and research participants by utilising a question-and-answer session before data collection, as well as attaching an information document to informed consent.
Detail on merging the data	Section 3.5 analysis of data, line 2-3	Information from the interview will be integrated with the information collected from the self-assessment.
Clarify order of tests	Section 2.3 data gathering tools, line 10-11	The occupational self-assessment will be performed after the semi-structured interview.
Add in information regarding drugs individuals may be on in the data information sheet	Appendix 11, line 11	Medication added.

APPENDIX 25

- **TURN-IT-IN REPORT**

Master research

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